

**Conductive Education: Why Parents of Disabled Children Turned To An  
Alternative System of Care.**

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**M.A. Dissertation.**

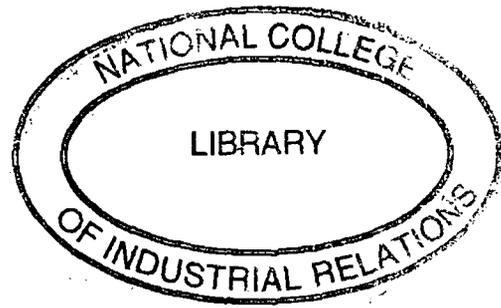
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## ABSTRACT.

**Conductive Education is a form of therapy for children with Cerebral Palsy and other disabilities. Many professional people have serious doubts about its effectiveness yet some parents of children with disabilities vote with their feet in its favour.**

**This thesis sets out to examine why they did so. The basic hypothesis underlying the thesis is that parents become very frustrated with the quality of provision which they experience from statutory bodies and others and that Conductive Education, on the contrary, provides them with a much more satisfactory and effective form of therapy.**

**A sub-text of this thesis is to examine the extent to which the parents decision to involve their children in Conductive Education represented a turning to a different type of provision as opposed to a turning away from the statutory provision.**

**The thesis proceeds in two sections. The first section comprises of interviews with six parents of children with Cerebral Palsy. This interview section discovers points in the development of the child in which parents experience often extreme difficulties.**

**The second section of the thesis is a survey of forty-six similarly placed parents designed to ascertain to what extent a larger majority of parents experienced similar kinds of difficulties.**

**The conclusion is that parents, in fact, turned to Conductive Education because of a perceived inadequacy of and extreme frustration with the quality of professional provision by the statutory authorities. They also, by comparison, perceived Conductive Education to be far more satisfactory in a variety of different ways. The thesis further establishes that this perception is not a comment on the merits or demerits of Conductive Education as a therapy or educational system, but merely records that parents perceive it to be far better than what is available by having recourse to statutory provision alone.**

## **STRUCTURE OF THE THESIS**

**This thesis sought to establish why, since 1986, many Irish families have turned to Conductive Education for relief of the problems caused by their child's disability. It also examines the parents perceptions of the comparative value of Conductive Education both before and after they experienced it.**

**The problems, as expressed by the parents, comprised not only the obvious ones presented by the physical difficulties experienced by the children. But parents also found themselves without information and unsupported by professionals at the times of the families greatest trauma. The majority felt frustrated and often distressed by the inadequacies of the therapeutic service available to their children. This frustration was, in many cases, increased by the parents perception that the service was delivered in a negative and insensitive manner.**

**Conductive Education, by comparison, seemed to offer the families and intensive method delivered in an optimistic and holistic manner.**

**This thesis is structured so as to present and prove its hypothesis in a clear and comprehensible method. Chapter 1. provides an out-line of the definitions, epidemiology and therapeutic approaches to Cerebral Palsy and Spina Bifida. Conductive Education is examined with the other therapeutic approaches and its recent impact in Ireland and Britain is reviewed. A summary of the medical and therapeutic services available to parents and children with disabilities in Ireland is included in this Chapter in order to give the reader an awareness of this provision.**

**Chapter 2. comprises of an analysis of in-depth interviews with six mothers of children with Cerebral Palsy. The interviews covered the families' experiences from the time when the first suspicions were raised about the children's development up to the time of the interviews. These interviews give a deep insight into the experiences of the families. They also identify a pattern of crucial stages at which the intensity of the frustration and dissatisfaction felt by the parents was increased. These emotions allied to the parent's perceptions of being isolated and alienated were significant in determining the parent's decision to travel to the Peto Institute in Budapest.**

**The areas of significance as identified by the interviews were instructive in the compiling of the questionnaire. The purpose of the survey was to establish whether the experiences of the parents who had been interviewed were typical of a greater group of those parents who had turned to Conductive Education. Chapter 3 analysis the responses to the survey and also includes the overall conclusions of the thesis.**

## **REVIEW OF THE LITERATURE**

### **RATIONALE.**

**When setting out the rationale for this review a number of important areas suggested themselves by reason of their importance to the thrust of the thesis. The literature on the topics which are of main concern to the thesis illuminate aspects and bring the arguments into sharper relief.**

**Thus, while it is necessary to speak in general about the origins of defining and classifying Cerebral Palsy and noting distinctions such as incidence and prevalence and causes of the condition, there is also a body of literature which deals with one of the focal points of the thesis, namely diagnosis.**

**A further concern of the thesis has been the availability and variety of forms of therapy for Cerebral Palsy. The different approaches need illumination if only to illustrate certain adaptations and policies of provision. Of course, the literature dealing with Conductive Education is of central concern to the thesis as many of its conclusions have been challenged and remain controversial, despite the fact that many parents vote with their feet in its favour and speak of it with almost universal approval.**

**The situation in Ireland is of central concern to the thesis and the review of the literature concludes with a treatment of provision - both statutory and voluntary and general specialist services which are germane to a proper understanding of the context in which the main actors and commentators of this thesis operate.**

## **CEREBRAL PALSY**

**Cerebral Palsy is not a single entity but rather:**

**"comprises a conglomerate of different non-progressive motor handicap syndromes, grouped together because they involve similar disorders of development and learning activities. The concept implies, however, a very mixed aetiology and pathogenesis." Olow [1986 p.60].**

**The heterogeneous nature of Cerebral Palsy leads and has led to difficulties in definition and classification. Definitions of Cerebral Palsy include that of Bax [1964 p. 295]:**

**"a disorder of movement and posture due to a defect or lesion of the immature brain."**

**and:**

**"A persistent *but not unchanging* disorder of movement and posture, appearing in the early years of life and due to a non-progressive disorder of the brain, the result of interference during its development. Persistence of the infantile type of motor control - such as may be seen in intellectually handicapped children, is not considered to be Cerebral Palsy." [Little Club 1959 pp27 - 35]**

Such definitions contain certain implications - that an insult has occurred which will cause a change in brain development. The lesion is permanent but the condition is not unchanging as growth and maturation will bring about changes. [McCarthy. 1992].

The first attempts to classify Cerebral Palsy are recorded as far back as Little [1862], Osler [1889] and Freud [1897]. Ingrams' [1984] historical review charts these and subsequent attempts at such a classification. Other authorities such as Alberman [1983] have identified the difficulties in classifying the Cerebral Palsies.

While acknowledging the difficulties, Bax, Robinson and Gath [1988 p.85] suggest a classification which they feel is both workable and useful:

*"Spastic forms* of cerebral palsy are those in which muscle tone and reflexes are increased. They can be subdivided into hemiplegia, affecting one side of the body; diplegia, affecting both sides, but the arms more than the legs; and quadriplegia, affecting all four limbs as well as the muscles used in feeding and speech.

*Dystonic forms* are those in which muscle tone is abnormal and variable, and differs from spasticity in that there may also be involuntary writhing (choreo-athetoid) movements.

*Ataxic forms* have mainly cerebellar signs - incoordination of voluntary movement.

In *hypotonic or atonic forms* there is general reduction in muscle tone. Some of these children will later develop signs of one of the other types of cerebral palsy, and some because of their associated mental status are probably better regarded as cases of severe mental

**retardation. The validity of including this term in the classification is doubtful.**

***Mixed types* are those which share the features of more than one of the above types. This group is comparatively large - at least one-quarter of all cases."**

**No classification is capable of giving an indication of the extent of the disability which a person with Cerebral Palsy may experience.**

**"A child with cerebral palsy may be one who is totally dependent and posturally disorganised, or one who is able to talk, walk and even run with little hindrance. "[McCarthy 1992 p.102].**

**Many children with Cerebral Palsy also have additional disabilities such as speech, visual and hearing impairments, epilepsy and mental retardation. [Olow 1986], [Ouvier and Collins. 1990]**

## **INCIDENCE AND PREVALENCE OF CEREBRAL PALSY**

**There is a difference between the incidence and prevalence of Cerebral Palsy.**

**Incidence is the number of new cases occurring during a certain time in a defined population at risk, e.g. premature babies. Because Cerebral Palsy is a heterogeneous condition that may arise at different stages of foetal development or early infant development and because many severely affected infants do not survive the neonatal**

period, it is considered that looking at the incidence of Cerebral Palsy is not very reliable or instructive.[Alberman 1983].

The prevalence of Cerebral Palsy is the number of cases during a certain time period and is expressed as the number of cases of Cerebral Palsy per 1,000 neonatal survivors. Studies including Cussens [1978], Hansen [1956], Stanley [1979 & 1982] have shown a consistency in prevalence rates. It is widely accepted that the prevalence of Cerebral Palsy in industrialised countries is 2 per 1,000. [Paneth and Kiely 1984]. Despite improved obstetric care in recent decades the prevalence of Cerebral Palsy has not significantly improved. One reason for this is that technological advances now enables doctors to keep alive babies - particularly preterm and very low birthweight babies - who would previously not have survived. Studies including Dale and Stanley, [1990], and Ellenberg and Nelson [1979] have demonstrated that improved mortality rates among low birthweight babies have been matched with an increased incidence of Cerebral Palsy.

#### CAUSES OF CEREBRAL PALSY.

The damage which causes Cerebral Palsy can occur before, during or after birth, or in a small number of cases may have a genetic origin. A Swedish study, [Hagberg, Hagberg & Onlow 1975] established that the damage in 7% of cases was sustained post-natally, in 49% of cases perinatally, in 27% of cases pre-natally and that it was impossible to distinguish in 17% of cases. Pollack [1993] cites an American study which established the aetiological factors thus:

**27.8% prematurity; 38.5% prenatal; 46.3% natal; 15.2% postnatal.**

### **DIAGNOSIS OF CEREBRAL PALSY.**

**Infants with severe forms of Cerebral Palsy are "readily identifiable at birth" [Harris 1987]. Although the milder forms of Cerebral Palsy have traditionally been considered difficult to diagnose [Ellenberg 1981]. Harris [1987 p.178] contends:**

**"With the advent of increasingly sophisticated neuromotor assessment tools, it is becoming possible to identify such infants before marked developmental motor delays are clearly apparent. In a high-risk infant follow-up study, 81% of children who went on to be diagnosed with cerebral palsy were retrospectively identified as abnormal or suspect at the four month evaluation based on scores of the Movement Assessment of Infants."**

**With such diagnostic tools, it is suggested by Olow [1986] that between 50-75% of cases of Cerebral Palsy can be identified at between 6 and 9 months of age. Ouvier and Collins [1990] cite an Australian study which established that approximately 50% of cases are diagnosed in the first year of life and 70% by the end of the second year. A recent study in the Western Health Board area - covering Galway, Mayo and Roscommon - established that 42% of children with a locomotive disorder surveyed were diagnosed before the age of six months, 14.5% between 7 and 9 months, 14% between 13 and 24 months, 17% over 24 months. 1.5% of the children were undiagnosed and 11% were catagorised as 'missing information.'**

**32% of children in the Galway area had been diagnosed after the age of twelve months, 47% of the children in the Mayo area and 36% of the children in the Roscommon area. [Gray. 1995].**

**There exists some conflict of opinion as to when parents should be informed of the possibility of a disability in a child. Olow [1986 p.64] believes:**

**"However anxious we may be to tell parents the truth as we see it, premature clinical decisions are undesirable."**

**and Illingworth [1984] argues that parents should not be informed of the possibility of a disability where uncertainty exists. Many studies, however, have established that parents need such information. [Bicknell 1983], [Fox, 1975]. Sloper & Turner [1993]. found that:**

**"Parents were.....more in favour of being given information about their child's disabilities at an early stage, even if this was based on suspicions rather than certainties."**

**Two British working parties, Carr and Oppe [1971] and Spain and Wigley [1975] found that parents wished to be told as soon as possible, sympathically, in private and with both spouses present. They also established that the person who informs them of the diagnosis is not automatically resented.**

Yet many parents perceive a delay in diagnosis possibly because it is often the parents who raise the first suspicions that their child might have some abnormality. [Glendinning 1983], [Hewitt 1970]. Sloper and Turners' [1993] findings that a strong connection exists between frank and open communication and acceptance of the diagnosis is supported by D'Arcy [1968], and Drillien [1964]. The Spastics Society Report "Right from the Start" [1993] documents the anguish of parents who suffer a delayed or inadequate diagnosis.

Delayed diagnosis does not just cause parental trauma and distress but can also interfere with the bonding processes between parents and children and parental awareness of a potential handicap can interfere with the establishment of secure attachments, [Battle 1974], [Blacher and Meyers 1983], [Kogan 1980]. Sutton [1989] describes how the very existence of a disabling condition can interfere with the essential bonding process between the infant and his family.

At whatever stage a diagnosis is made on-going information and support is vital. Yet there are difficulties and inadequacies in providing such information [Attwood 1977], [McAlister et al 1973], despite the need for such information being documented [Tarron 1980] and the evidence of the trauma that the absence of such information causes. The Gray [1995] study in the West of Ireland established that 45% of parents whose children had a locomotive disorder, stated that they received no information at the time of diagnosis and 49% said that no counselling had been available to them at this time.

**Delayed or inadequate diagnosis and/or inadequate information and support is also significant in that it can lead to a weakening of the relationship between the parents and professionals. Both the Court Report [1976] and the Warnock Report [1978] stress the importance of the parent/professional relationship being based on partnership and parity of esteem.**

**Prompt diagnosis is also important because it facilitates early intervention. Guaralnick and Bennett [1987 p.18] state that:**

**"A considerable theoretical and empirical literature is now available indicating that developmental outcomes can be substantially altered by the nature of the social and physical environment during the first years of life [Sameroff and Chandler, 1975: Wachs and Gruen, 1962]."**

**Studies have quantified the benefits of early intervention: Guaralnick and Bennett [1987] established that such intervention reduced the effect of disabling conditions: Soboloff [1981] reported earlier mobility for children who received early intervention and Kanda [1984] established earlier and steadier walking for such children.**

## TREATMENT OF CEREBRAL PALSY.

There are many approaches to the treatment of children with Cerebral Palsy. [Scrutton 1984], [Gillette 1969], [Levitt 1976]. Individual therapists will usually have been trained in one approach and will base their treatments on that one approach. [Jones et al. 1992]. Eckersley and King [1993 p.324] in 'Elements of Paediatric Physiotherapy' state:

"it is probably more helpful for the newcomer to paediatrics to work with one philosophy initially, in order to gain a measure of expertise and confidence. The therapist should always be prepared to examine and use other ideas as and when appropriate so that the therapeutic approach becomes broad based and capable of adaptation to the needs and circumstances of individual children and their families. Although 'dabbling' in concepts without any real skill or thought can invite confusion or misunderstanding, it is only by keeping minds open to new ideas and challenging older and possibly more accepted ones that the therapy approaches to the management of childhood disorders can continue to develop."

### **W.M. PHELPS.**

An American orthopaedic surgeon, W.M. Phelps, was an early pioneer in the treatment of children with Cerebral Palsy and the first to encourage therapists to come together into cerebral palsy habilitation teams [Phelps. 1952].

Phelps diagnosed children into five classifications of Cerebral Palsy and according to these classifications he treated children with combinations of his fifteen 'modalities' of treatment. Specific

modalities were considered beneficial for some classifications of Cerebral Palsy while contraindicated for others. The modalities are: (1) massage, (2) passive motion, (3) active assisted motion, (4) active motion, (5) resisted motion, (6) conditioned motion, (7) synergistic, i.e. confused, motion, (8) combined motion, (9) relaxation techniques, (10) movement from relaxation, (11) rest, (12) reciprocation, (13) balance, (14) reach and grasp, (15) skills of daily living.

Phelps also advocated the extensive use of braces and calipers and of muscle development [Phelps 1953], [Egel 1948].

#### **NEUROMOTOR DEVELOPMENTAL APPROACH.**

Another early pioneer in the treatment of Cerebral Palsy was Eirene Collis who developed a **NEUROMOTOR DEVELOPMENTAL APPROACH**. She disapproved of the treatment of Cerebral Palsy being shared between various therapists e.g. physiotherapist, occupational therapist, and speech therapist and advocated the establishment of a 'cerebral palsy therapist'. The neuromotor developmental approach insists on a rigid developmental sequence with a child not being permitted to perform motor skills above his or her developmental level. Thus, if a child is learning sitting skills he or she would not be permitted to practice walking skills.

Collis believed that early intervention facilitated a better result and that the child's whole day and all his activities including feeding, toileting, and washing should be considered part of the scheme of management. [Collis 1953].

**NEURODEVELOPMENTAL TREATMENT WITH REFLEX  
INHIBITION AND FACILITATION.**

**This approach was developed by the husband and wife team Karl and Berta Bobath [Bobath and Bobath 1975], [Bobath 1971], [Bobath 1979], [Bobath 1965]. It is:**

**"arguably the most familiar and widely used approach known to British physiotherapists working with children with neurological disorders" [Eckersley and King 1993 p.334].**

**It is the method used in most Irish Specialist Clinics and 'nearly all' the physiotherapists in the Central Remedial Clinic have completed post-graduate programmes in the Bobath system. [People First 1995]**

**The Bobaths held that it was essential to normalise the postural tone of a child with Cerebral Palsy by inhibiting tonic reflexes and primitive reflexes. These, once inhibited, can be replaced by more mature postural reflexes. They taught that the neurological development of a child with Cerebral Palsy had been arrested at a particular, immature level and that the infants' movements were dominated by the involuntary reflex movements of that level. It is therefore essential that these reflexes be removed in order that the child can progress beyond that level.**

**Sensory motor experience is used to break down abnormal motor patterns and give a child the experience of normal tone and movement. Facilitation is used to encourage normal movement patterns through the experience of these patterns.**

**The Bobaths stressed that early identification of Cerebral Palsy was crucial. Treatment potential was presumed to be optimised if treatment can begin within the first year of life when infants would normally be achieving developmental milestones [Bobath 1967].**

**The Bobaths emphasised the importance of the all-day management of the child's day. To this end parents' were to be a fundamental part of the child's therapeutic team [Finnie 1974]. Enabling a child to experience optimal normal movement with normalised tone throughout the day was a basis for the achieving of that normal movement.**

**The earlier Bobath insistence on a strict sequential developmental progress was later modified. [Bobath and Bobath, 1984]**

#### **SENSORIMOTOR APPROACH.**

**The SENSORIMOTOR APPROACH to treating Cerebral Palsy was developed by Margaret Rood [Rood 1954, 1956, 1962,]. This approach is based on the premise that fundamental reflex patterns which exist at birth are modified through sensory stimuli until the highest control is achieved at the conscious cortical level. In the case of children with Cerebral Palsy, motor response could be achieved reflexly through correct stimulation, and through repetition correct motor patterns could be established.**

**Like the Neurodevelopmental Treatment approach, it aims to facilitate a subconscious movement response in the child. But unlike that approach it uses a variety of methods of sensory stimulation such**

as vibration and tapping, stretching, joint compression and skin stimulation such as massage, brushing (by hand or with soft bristles) and icing. [Stockmeyer 1972], [Goff 1969], [Goff 1972].

The Sensorimotor Approach also insists on sequential development.

#### **PROPRIOCEPTIVE NEUROMUSCULAR FACILITATION.**

**PROPRIOCEPTIVE NEUROMUSCULAR FACILITATION (P.N.F.)** was developed by Kabat, Knott and Voss. [Knott and Voss 1968], [Voss 1972], [Kabat 1961], [Kabat 1959]. Unlike other methods which work to strengthen individual muscle groups, P.N.F. facilitates patterns of movement that have functional relevance for the individual such as feeding or walking. These patterns are spiral and diagonal with a synergy of muscle groups and consist of flexion or extension, abduction or adduction, internal or external rotation.

As in the Sensorimotor approach the method uses sensory stimulation to facilitate movement. Such stimulation includes stretch, touch, pressure and proprioception (muscles contracting against resistance).

Movement patterns in this method are also developmentally sequenced.

#### **PROGRESSIVE MOVEMENT PATTERNS.**

The **PROGRESSIVE PATTERN MOVEMENTS** method was developed by Temple Fay. [Fay 1954], [Fay 1954], [Fay 1954] who worked on the premise that a child with Cerebral Palsy should be taught to move according to his or her evolutionary development.

**Human ontogenic development is based on phylogenetic development in the evolution of the species. Movement sequences should build up from reptilian squirming and amphibian creeping through mammalian crawling on all fours to erect primate walking. A human with an abnormal cerebral cortex should be able to carry out the primitive squirming of those lower animals who possess only a simple nervous system. These basic movements will stimulate patterns of movement and reflexes.**

**The creeping motion is taught passively by 'patterning'. This involves three persons turning the child's head and limbs in a set pattern for at least five minutes at least five times daily. As the child progresses he or she can take over the patterning.**

**A child may not progress to another patterning level until he is proficient in the previous one. The strict patterning sequence consists of: prone lying, primitive homolateral creeping, contralateral creeping, crawling, bear or elephant walking (on hands or feet), and walking.**

#### **DOMAN-DELACATO.**

**The DOMAN-DELACATO METHOD follows the Temple Fay method but also adds other modalities. The method is premised on the belief that a highly systematic movement and sensory regime can stimulate undamaged brain cells to bring about the integration of the sensory and motor disorganised by the brain damage. [Doman 1974]**

**Apart from the patterning techniques used in the Temple Fay method, the Doman-Delacato method also uses vestibular stimulation - which may involve swinging a child upside down , inhalation of**

**C.O.2. by placing a mask over the mouth and nose, restriction of fluids and deep breathing techniques and the use of flash cards and sensory stimulation.**

**A child is not permitted to progress to a higher patterning level until competent in a lower one.**

**The Doman-Delacato method has provoked much controversy and has been criticised for being too rigorous and demanding on both the child with Cerebral Palsy and his or her family and for provoking unrealistic expectations. [Cummins 1988].**

#### **VOJTA METHOD**

**The VOJTA METHOD was developed on the work of Temple Fay and Kabat. [Vojta 1974].**

**The method can be used as a prophylactic approach with early diagnosis being made according to a series of postural reflex tests. Early treatment might then serve to prevent Cerebral Palsy. [Brandt 1980].**

**In this method the therapist facilitates reflex creeping and rolling patterns by 'triggering' appropriate reflex zones with sensory stimulation. The method also uses resistance for the action of muscles. Through resistance the tonic or phasic action may be obtained.**

## **CONDUCTIVE EDUCATION.**

**This literature covers the whole area of Conductive Education and repeats itself throughout. In the interests of clarifying what is covered perhaps a resume of what it contains would provide a background and a context in which the main focus of the thesis can be understood. Further reading on this area could include: Hari and Tillemans [1984], McCarthy and Martin [1992], Cotton [1975], da Salva [1984], Titchener [1982].**

**Conductive Education was developed by Andras Peto and differs fundamentally from the other methods used with children with Cerebral Palsy in that it was developed as an educational rather than a medical method.**

**Peto considered motor disorders such as Cerebral Palsy to be learning difficulties and therefore Conductive Education strives to teach a child to overcome the disorder and achieve 'orthofunction'. Conductive Education does not seek to cure the underlying disorder but aims to teach the child to function independently and thus to prevent the condition from becoming a disabling one. Children are taught to learn, through activity, solutions to the difficulties which their motor disorders present. Children are not taught how to move or function but to find a path to overcome their disorder.**

**'Orthofunction' is achieved when a person can function adequately in society without aids and appliances.**

**This education is a daylong process and takes a child through his daily activities from rising, washing, dressing and feeding to reading,**

**writing and leisure activities. Hungarian children reside in the Institute and live to a fixed daily timetable.**

**Conductive Education strives to achieve 'Orthofunction'. Orthofunction is achieved when a child can function adequately in society without aids. The Andras Peto Institute for the Motor Disabled claim a 70% success rate in achieving orthofunction.**

**Children are set individual goals and these are broken up into `task series`. The tasks are not abstract but are practised and reinforced throughout the daily programme until they become a habit. The child will then move on to the next task and this continues until the goal is achieved. The task is always one which is achievable and the child's success encourages and motivates him to achieve successfully the next task and ultimately the goal.**

**Conductive Education uses `rhythmic intention` to link speech and action to reaffirm constantly and reinforce each other. A child expresses his intention and performs the movement. Dynamic speech is often used and the rhythm can be used to regulate the rhythm of the movement. Thus a child will say, either verbally or silently, "I lift my arm up, up, up, up." or "I lie down, 1, 2, 3, 4, 5."**

**Every daily activity in Conductive Education takes place within a group. Each group comprises approximately twenty children and functions as a unit. As well as providing a sense of community and constant peer group interaction, the group is considered to have a powerful motivational force. As one child in a group achieves a task he is encouraged and applauded by the other children who are then**

spurred on to their own achievements by the success of their colleagues. The group is also felt to relieve the child of the pressure of a one-to-one relationship. The child is free to work within the group to a common goal without oppressive scrutiny, encouraging him to develop his own individuality. The group is said to provide security, motivation and stimulation.

Conductive Education is carried out by Conductors. A Conductor is trained for four years to teach the children in all aspects of motoric, academic and social education. The Conductor educates the children from waking to sleeping. They establish the goals and tasks for the groups and the individual children and find ways of reinforcing any progressions. Three Conductors generally work with any Conductive Education group. A Conductor does not move a child's limbs but facilitates a child to move to the best of her ability with minimal physical intervention on the part of the Conductor. Conductors use music and song to a great extent to motivate and interest the children.

Conductive Education uses only a few functional pieces of furniture. A wooden slatted table called a 'plinth' serves as a bed, a table and a base upon which to perform motor tasks. All children walk from one place to another and wheelchairs are never used. If a child is unable to walk unaided she pushes a 'ladderback chair' with whatever support necessary from a Conductor. Some children wear light splints.

## **CONDUCTIVE EDUCATION IN BRITAIN AND IRELAND SINCE 1986.**

**Conductive Education appeared to burst from nowhere into the public conscious with the screening of the B.B.C. documentary film, 'Standing Up For Joe' in April 1986. This documentary followed an English boy, Joe Horsely, through his assessment at the Peto Institute in Budapest and contrasted the provision there with what was available to Joe at home. The documentary ended with the statement that the Peto Institute was closed to further 'Western' applicants, but not withstanding this the B.B.C. received 11,000 'phone calls enquiring about the Peto Institute and the Hungarian Embassy was also inundated with enquiries.**

**Almost immediately after 'Standing Up For Joe' was transmitted, the British and Irish local and national newspapers were carrying articles about children with Cerebral Palsy and Spina Bifida whose families were raising money to finance visits to the Peto Institute in Budapest. Headlines such as:**

**"Join The Sunday Times Appeal And Help Disabled Children Learn To Walk" [Hodgkinson, 1987].**

**"At three, Emma could only crawl, In six weeks she was walking to her mother's embrace." [Levy, 1989].**

**"Walking against the Odds. Crippled British children find new hope in Budapest" [Shepherd, 1987].**

**"Tracy is given chance to walk." [McCabe, 1990].**

**"Thriving on the Hungarian treatment." [Smyth, 1990].**

**"Helping Deborah walk to happiness." [English, 1990].**

**In Ireland such stories comprised the only coverage which was given to Conductive Education apart from the very occasional article such as**

**"Peto 'not the answer for disabled children.'" [Ni Chríodain. 1990].**

**In this article, Tony Jordan, principal of Cerebral Palsy Ireland's Sandymount School, expressed concern:**

**"about a growing belief that disabled children can only be helped by expensive treatment at the Peto Institute."**

**In Ireland, families went to and continue to go to the Peto Institute very much on an individual basis. Several attempts have been made to organise pressure groups to lobby for the introduction of Conductive Education into Ireland and for the training of Irish persons as Conductors. Such groups - Association for the Promotion of Conductive Education and The Irish Peto Parents - have been**

largely unsuccessful in generating much interest except in some localised instances. However, some organisations working with children with disabilities are now committed to using Conductive Education principles with the children under their care. [Conduit, 1995].

In England, parents mobilised fast and efficiently. Almost immediately after the 'Standing Up For Joe' programme, a parent pressure group - Rapid Action For Conductive Education [R.A.C.E.] was formed. M.P.s were lobbied, the Houses of Parliament were picketed and questions were asked in the House of Commons. [The Conductor, 1990], [Parliamentary Debates, 1992].

This resulted in the establishment of the Foundation for Conductive Education and in September 1987, the Birmingham Institute for Conductive Education was opened with a grant from the government. The Institute had three objectives: [1] to train British people as Conductors, [2] to provide Conductive Education for the children who would attend the Institute, and [3] to make possible an evaluation of Conductive Education as provided by the Birmingham Institute for Conductive Education. [Lambert. 1993].

In 1988 the Foundation sent its first trainees to Budapest. In the summer of 1990 the Spastics Society sent 12 trainees to the Peto Institute in Budapest adding to the 15 which the Foundation had sent by this date. In 1992 the British Government pledged £5 million over

**four financial years towards the building of a £45 million International Institute for Conductive Education in Budapest in order to secure a guaranteed number of places for British children in the new Institute. In 1989 the Children's Act enabled Local Education Authorities to finance the sending of handicapped children abroad for treatment. [Schedule 12, para. 36 of the Children's Act makes addition to the Education Act 1981]. This meant that families could apply to their Local Authority to fund their visits to the Peto Institute.**

**Alongside these developments there emerged a lively and heated debate. Articles such as:**

**"Conductive Education for motor disorders: new hope or false hope." [Beach 1988 p.211].**

**in which Beach called for the extra resources which were being spent on Conductive Education to be redirected to those families who needed a more intensive therapeutic service than they were currently receiving. Thus, he wrote,:**

**"A tide of enthusiasm for improved treatment for motor disorders from the media could then be harnessed to a more achievable goal than the elusive one of Conductive Education."**

and

**"Conductive Education: if it wasn't so sad it would be funny." [Oliver 1989].**

**in which Conductive Education was characterised as 'theoretically unproven, practically unsubstantiated and ideologically unsound.' Oliver [1989 p.119] wrote:**

**"The nightmare of Conductive Education is unachievable because nowhere in human history have the *different* been turned into the *normal* and neither medical science nor other rehabilitative techniques or educational intervention can assist in this process. The reason is very simple: normality does not exist. Someone else, not very long ago, had a vision of normality associated with blond hair and blue eyes, and look where such a vision got him."**

**These sentiments were answered by articles such as "A response to R. Beach 'Conductive Education for Motor Disorders: New Hope or False Hope.'" [Sutton, 1987]. and "Conductive Education: a Rejoinder." [Beardshaw, 1989].**

**In 1988 the English Chartered Society of Physiotherapy issued: "Conductive Education: a Statement." which called for an end to the bitter row about Conductive Education and a facing of realities. The press release stated that the media coverage about Conductive**

**Education was partial and did not acknowledge the excellent work being carried out in England or the:**

**"Budapest failures and the children who return to Britain in a poorer condition than when they went out."**

**Sutton published: "The Impact of Conductive Education." in 1987 in which he characterised the Statement of the Chartered Physiotherapists as inconsistent and inaccurate.**

**Questions were raised about the lack of scientific and methodological data about Conductive Education and the theoretical basis on which the method was founded. [Sutton, 1986]. In 1988 the English translation of "Conductive Education" by Maria Hari (Director of the Peto Institute since Andras Peto's death) and Karoly Akos was published which presented the theoretical background, practice and achievements of Conductive Education. The Foundation translated and published much documentation concerning the method of Conductive Education including: "Intention: The Principal Hypothesis of Conductive Education" [Hari 1991] and "The Human Principle in Conductive Education". Hari [1988].**

**Questions were raised as to the 'transplantability' of Conductive Education. [Bairstow and Cochrane 1993]. Bairstow, Cochrane and Rusk [1991] criticised the Peto Institute for being overly selective,**

**accepting only those children who would progress well under any system.**

**The Association for Spina Bifida and Hydrocephalus sent a 'fact finding mission' to the Peto Institute which came back:**

**"unable to recommend the work of the Peto Institute in regard to children with Spina Bifida." [B.B.C. Transcript, 1990].**

**Parents were accused of being gullible and / or seeking an easy option:**

**"Parents have a perception of wanting more treatment in Britain but I wonder how much they really want someone else to do the work for them." [Sobkowiak, 1991 p.15].**

**Parents and the British Government were berated for the amount of money which they were diverting towards Conductive Education:**

**"If you have additional resources available, invest the money here in the British system, not in the Birmingham project or in Hungary. The cost of sending one child to Hungary would pay for a therapist who could treat 50 children for a year." [Farrar, 1993 p.51].**

**While the controversies about the value of Conductive Education continued, another argument ran in parallel. Ester Cotton, physiotherapist, visited the Peto Institute in Budapest several times in the 1960s and, impressed by what she saw, was encouraged by Andras Peto to 'give it a go' [Cotton, 1995] in England. Through her enthusiasm and the imparting of her knowledge to other professionals, schools and units within schools run by the Spastics Society established programmes which were run along her principles. However, the legitimacy of Ester Cotton's principles as Conductive Education, or other modifications of Conductive Education, are the subject of controversy amongst both those involved in the Birmingham project and by Andras Peto's successor, as this excerpt from an interview with Maria Hari illustrates:**

**Pat Scowen: 'Is it true, Dr. Hari, that you don't approve of people doing Conductive Education by half measures? Some people have tried to set up a modified form in this country'**

**Dr. Hari: 'No, what they're doing is not Conductive Education. Do you know Goethe's poem about the Sorcerer's Apprentice? He thought he could practice the magic when his master was not there, but when he tried it he found it didn't work properly.' [Scowen, 1987].**

**Evaluations and studies have consistently failed to establish the value of Conductive Education or Conductive Education type methods over traditional Western methods of therapeutic provision. Many schools, units and projects have been run along Ester Cotton's principles as devolved from Andras Peto. Of the evaluations of these, only one -**

[Jenquist, 1978]. was able to establish any appreciable improvement in the children involved. Other studies failed to detect any superior benefit to those children involved in projects using Conductive Education methods. [McCormack, 1974], [Clarke, 1973].

The evaluation study of the Birmingham project was published in 1993. [H.M.S.O, 1993]. This compared the progress of the 10 children involved in the Birmingham Project with a control group of children in a 'special' school on Manchester. The result showed little difference between the progress of the two groups. Where a difference existed, it tended to show the Manchester [control group] as achieving more significantly. Before this evaluation report was even published, criticisms were being lodged on behalf of the Birmingham Project on the methodology and conclusions of the evaluation.

The debate as to the efficacy of Conductive Education, the cost of Conductive Education and even the essence of Conductive Education proceeded and proceeds. Meanwhile, parents of disabled children continue to travel with their disabled children to Budapest, employ Hungarian Conductors to work with their children at home, involve their children in groups which use 'Peto principles' or 'Conductive Education principles' either within school units or by organising summer camps for their children. No-one is sure how many parents have involved their children in Conductive Education. But a perusal of any edition of 'The Conductor' published by the Foundation For Conductive Education would show strident efforts by parents, and sometimes professionals, to involve disabled children in Conductive

**Education projects in Budapest, Ireland, England, Hong Kong, Japan, Australia, Germany, Israel, Austria, etc. And studies of parental perceptions of Conductive Education or projects using Conductive Education principles have repeatedly shown a high level of parental satisfaction. [Cooper, 1986], [Hill, 1990], [Munro 1992/1993].**

### **MEDICAL AND THERAPEUTIC SERVICES FOR PHYSICALLY DISABLED CHILDREN IN IRELAND.**

**Physically handicapped children in Ireland may receive medical and therapeutic services through either their local Health Boards or through Voluntary agencies or through both. [Gray, 1995].**

**The structures of the Health Services in Ireland are well documented by Kelleher [1993], Curry [1980], and Hensey [1979]. Services to physically handicapped children - which would include physiotherapy, occupational therapy, speech therapy, aids and appliances, psychological and social work service - are delivered through the Community Care programme of the Health Boards. [Kelleher, 1993].**

**Health Boards may either deliver the service directly or arrange for their delivery through Voluntary Organisations. Section 65 of the Health Act, [1953] enables Health Boards to fund organisations which provide 'similar or ancillary' services to those provided by the statutory bodies and section 26 of the Health Act, [1970] allows for**

**Health Boards to arrange for services to be carried out on their behalf [Report of The Commission on Health Funding, [1989]. Such 'similar or ancillary' services are delivered by Voluntary Organisations.**

## **VOLUNTARY ORGANISATIONS.**

**VOLUNTARY ORGANISATIONS play a major role in the provision of a wide range of services in Ireland. They not only provide services and complement statutory services but - most notably in the area of mental handicap - they have provided the main thrust in the development of understanding of the disability and the extending of the parameters of care and remediation. Many of the services which are now delivered by the State were first developed by Voluntary Organisations who identified a need and organised a humanitarian response to this need. Thus the shape of existing services has been greatly influenced by Voluntary Organisations. [Shaping a Healthier Future, 1990]. [Report On The Commission on Health Funding, 1989].**

**Some of the larger Voluntary Organisation are funded directly by the Department of Health which gives them a certainty of their basic incomes although all Voluntary Organisations also rely on fund-raising. The other Voluntary Organisations depend on annual grants from local Health Boards and Kelleher [1993] asserts that:**

**"Expenditure under this heading amounts to more than 10% of the Western Health Board's total expenditure"**

**Difficulties and deficiencies are created by this method of service delivery and the Report of the Commission of Health Funding, [1989 p.342], reported that it lead to poor cooperation between the the statutory and voluntary sectors and to a lack of comprehensiveness in the provision of services and called for an approach**

**"which will ensure that all publically-funded agencies, whether statutory or voluntary, work together in the most efficient and effective way, without jeopardising the independence and flexibility which are the voluntary organisations' most important attributes."**

#### **DIAGNOSIS IN IRELAND.**

**Under section 66 of the Health Act, 1970 each Health Board is required to offer a pre-school Child Health Examination which should offer developmental paediatric examinations at approximately the ages of six, twelve and twenty-four months in towns or centres with a population of 5,000 or more. In other parts of the country this function is provided by Developmental Clinics or, in rural areas, by home visits by the Public Health Nurse and the purpose of such screening is the early detection of handicap. Where developmental delay is detected, whether by such clinics, the Public Health Nurse or**

by General Practitioners, the child may be referred to specialist clinics. [Kelleher 1993].

#### **SPECIALIST CLINICS.**

The Central Remedial Clinic is the largest centre for the physically disabled in Ireland, its physiotherapy department has more than 1,300 clients on its books - with 80% of these being children. [People First, 1995]. Children from all parts of Ireland are referred to the Central Remedial Clinic for diagnosis, supervisory physiotherapy services, seating clinic, micro-electronics, and consultant orthopaedic services.

In the Gray [1995 p.21] study parents were asked about attendance at a specialist clinic or centre. Seventy percent had attended a centre outside the Western Health Board area:

**"While some of the children attended on an occasional basis more than half attended regularly, ranging from twice a year to once monthly.**

**The vast majority of the parents [93%] said that these clinics should be provided locally. Reasons for attendance at these centres included the fitting of aids and appliances, occupational therapy, psychological assessments as well as specialised surgery and therapy. Parents cited difficulties associated with the cost of travel and disruption to family life where a child had to travel long distances several times a year."**

**Other specialist clinics include the Sandymount School and Clinic and the Cork Spastics Clinic. In recent years Cerebral Palsy Ireland has provided local therapy services in areas in which the statutory provision was inadequate. In addition it has established several therapy or Child Development Centres - many of which run in conjunction with the local Health Boards - with the aim of providing comprehensive services for the disabled children of that area.**

### **SPINA BIFIDA**

**Four of the families who were involved with the survey section of this thesis had children who had Spina Bifida rather than Cerebral Palsy. Therefore a brief out-line of the condition Spina Bifida will now be included.**

**Spina Bifida is a congenital condition caused by the failure of the neural tube to fuse in the very early stages of embryonic development. [McCarthy, 1992]**

**The incidence of Spina Bifida in Ireland was established by The Special Education Review Report [1993] as being 3 cases per 1,000 live births annually. The Health Promotion Unit of the Department of Health states:**

**"2 in every 1,000 newborns in Ireland have NTDs (Neural Tube Defects). This is significantly *higher* than in many other European countries".**

**There are several understood causes of Spina Bifida. While genetics are a causative factor in some cases, studies have now firmly established a link between a folic acid deficiency and Spina Bifida. All women are now advised to take a folic acid supplement prior to conceiving. [Wald et al. 1991]. [Department of Health, Dublin].**

**Spina Bifida is categorised into three main types - Spina Bifida occulta, Spina Bifida cystica meningocele and Spina Bifida cystica myelomeningocele.**

**In Spina Bifida occulta the lesion is not visible or visible only in terms of an abnormal hairy patch or dimpling or thickening of the skin.**

**Spina Bifida cystica meningocele is the less common and generally less serious of the Spina Bifida cysticas, while Spina Bifida cystica myelomeningocele is the most common and generally the most severe form.**

**The extent of the effect of Spina Bifida will depend on both the level of the spinal lesion and its severity. While meningocele lesions are usually less damaging than myelomeningocele lesions, they are still capable of destroying the spinal cord below the lesion. Bedford [1993 p.131] out-lines some of the problems which children with a myelomeningocele may experience, depending on the location and severity of the lesion:**

**"Some degree of flaccid paralysis with sensory loss; incontinence of bladder and bowel; about 80% will also develop hydrocephalus; learning difficulties, general and specific, which may be associated with hydrocephalus; many have a low average intelligence, clumsy hand function and visuoperceptual problems; some have additional abnormalities to their urinary, alimentary and skeletal systems, e.g. club feet, cleft palate; children with spina bifida may also be born with deformities of the legs and feet, which may be due to muscle imbalance or be the result of intrauterine pressure on flaccid legs."**

**According to Bedford [1993 p.40] the aims of a physiotherapist working with children with Spina Bifida are to:**

**"Treat and prevent deformities. Strengthen arms and improve hand function. Improve head control, trunk control and balance. Encourage early standing and mobility using adequate aids. Provide guidance on management and supervision of the provision of equipment."**

**Information on the manifestations, implications and management of Spina Bifida can be obtained from sources such as Minns [1986], Anderson and Spain [1977], and McCarthy et al. [1992], Lorber [1971].**

## **CHAPTER 2.**

### **AN ANALYSIS OF INTERVIEWS WITH SIX PARENTS OF CHILDREN WITH CEREBRAL PALSY, WHO JOURNEYED TO BUDAPEST WITH THEIR DISABLED CHILDREN, FOR THERAPY AT THE ANDRAS PETO INSTITUTE THERE.**

#### **PURPOSE OF THIS CHAPTER.**

The basic question of this thesis is why do parents take on a long journey, at some expense to themselves and hardship to themselves and their families in order to seek a therapy which many claim to be of dubious value.

It was thought at the outset that an interview with six people might establish a preliminary hypothesis.

Did parents go because they were lured by some kind of "magical" illusion about the effectiveness of the treatment available at the Peto Institute?

Did they have a more concrete proof or conviction which motivated them?

Was there some common history which, constructed in a certain way, might explain what on the face of it is quite an extraordinary phenomenon, an exodus to some kind of promised land, based on their sense of oppression or frustration?

**The preliminary examination establishes beyond doubt that at certain points in dealing with a child with cerebral palsy there was an intensified feeling of frustration, that built up over time to an equally intense sense of relief when parents were offered something positive, concrete and effective for their child, something which they as parents could fully understand and in which they could participate.**

**The nodes of tension and areas of dissatisfaction around which the frustration built up occurred more or less regularly in each case examined. They were diagnosis, early therapeutic provision, schooling and post-Peto therapy. To this dissatisfaction the Peto experience seemed to provide a ready antidote.**

**In this preliminary exposé some of the ground to the previous chapter, the examination of the literature, is repeated and this time not as a review, but by way of illuminating in greater depth the contextual variations of different accounts and experiences.**

#### **BASIC ARGUMENT.**

**Parents went with their handicapped children to Peto not in pursuit of magic but for a variety of definite and very specific reasons which are largely concerned with various extremes of frustration at both the inadequacies of available provision and the manner in which this provision was administered. In contrast, the Peto Institute offered a sense of acceptance and a feeling that something practical, useful and effective was being offered to their children.**

## **OVERVIEW**

**The sense of frustration in the documentation for this study occurs at different, crucial stages in the development of the child, moments when crucial decisions have to be made such as at diagnosis, when early therapy is offered and when the child enters the school system.**

## **PETO INSTITUTE.**

**The contrasting evidence concerns the Peto Institute which is characterised by a countermanding sense of acceptance and a sense that something practical and effective can be done for the child with a disability. Each section of the chapter which follows is a part of a logical argument which demonstrates the force of the evidence in interconnected and related but in very different ways.**

## **METHODS OF PRESENTATION.**

**The method of presentation adopted for this part of the study is to loosely group the experiences of parents under different headings: diagnosis, therapy, schooling and the Peto Institute, and present it in a discursive manner that is divergent rather than focused on single line arguments. The reason for adopting this style of presentation is because the nature of the interview responses runs this way, and because the reader needs to capture the flow of the discourse and the feelings of the interviewee. Involvement with the subject will give an impressionistic sense of the content as well as a sense of control of the logic of the argument. Some quotations from the literature are also**

**included in this presentation to illuminate the core of the argument being presented and to give added thrust and direction.**

**The interviews themselves were free-flowing within minimal constraints. The interviewees were made aware that the areas of interest were: the time around diagnosis; their perceptions of the availability and quality of therapeutic services; their experiences of the education system vis-à-vis their child with a disability; the decision to turn to Conductive Education; their experiences of Conductive Education and the reaction of the professionals to their decision to attend the Peto Institute.**

**The interviews flowed logically from one topic to another with little prompting. The recall of each mother was sharp and unhesitant and the distress caused to them by some of their experiences was very evident.**

## **DIAGNOSIS**

**The first occasion of frustration seems to occur at the time of diagnosis or during the search for a diagnosis. The evidence from the interviews demonstrates that parents experience varying degrees of frustration and sometimes extremes of frustration at the time of diagnosis. This sense of frustration is experienced in a variety of different ways: rejection, wrong diagnosis, withdrawal of services, non-disclosure, sense of negative social attitudes towards disability, carelessness, lack of facilities and lack of caring professional approach and consideration.**

**"No-one wants a handicapped child. We all want fit, handsome, intelligent children who will do well in the competitive society we live in, and 'be a credit to us'".  
[Bavin 1974 p.12]**

**For the six families in the in-depth study the realisation that their babies had problems came in different ways and when the babies were at different stages of development. Bavin [1974 p.13] says:**

**"The first shock of being told of the child's handicaps is greatly lessened if the telling is done skilfully and with compassion by a doctor who offers to help the family through the early problem period."**

**If this statement sets the standard then none of these families received adequate care. The family which received the best diagnosis were parents who had no major concerns about the child prior to diagnosis**

and were told of the child's difficulties frankly and were warned about his future:

**"Stephen was about a year old and he wasn't sitting up on his own so we were a bit worried because he had had a lot of chest illnesses so we knew he was behind and he was only three pounds so we weren't expecting wonders. So we went to [doctor] who is a paediatrician in [hospital] and he gave us the diagnosis of Cerebral Palsy and we were devastated, absolutely devastated. I remember his telling us that we would have an up-hill struggle all the way, that we would have to fight for the child from the word go. If he got anywhere it would only be because we fought for it"**

**One child in the interview study was six month old on diagnosis, two were one year old, one was fourteen months old and one was two years and three months old at the time of diagnosis. Parental concerns about one child were picked up on by a Medical Officer at a Developmental Clinic. This Medical Officer referred the child to a paediatrician who diagnosed her as suffering from Cerebral Palsy at seven months. In the case of another child a Doctor at a Developmental Clinic acknowledged that the six month old child had reached none of the expected developmental milestones but marvelled at the fact that she survived her premature birth.**

**In the case of Martin, the doctors involved had clearly made a diagnosis and were reviewing him on a weekly basis without giving the parents any indication that they had made such a diagnosis.**

**When after a year and tiring of a long weekly journey, the mother questioned the doctors she was told:**

**"Well, you know that your child is mentally and physically handicapped"**

**The parents had in fact no reason to think this and the doctors' previous demeanour had given no hints about a possible disorder. Immediately after this abrupt diagnosis the family was referred to a specialist in the [clinic] who gave a diagnosis of Cerebral Palsy. The query must be raised as to why the specialist referral was delayed until the parents questioned the purpose of their visits to the Hospital. An even more extreme example of doctors making a diagnosis without informing the parents, involved a boy who was not from one of the families in the in-depth study. The child received physiotherapy on a regular basis without the parents ever being informed of the nature of the problem. The first time they heard the term Cerebral Palsy applied to their child was when the Development Officer of a Voluntary Organisation came to visit them as parents of a child with Cerebral Palsy.**

**There is some debate as to when parents should be told that their child might have a disability. Bax, Robinson and Gath [1988 p.109] state:**

**"There are those who believe that where a handicapping condition is untreatable, early identification is not helpful either to parent or child. Some doctors in the past delayed telling parents that**

**their child had Downs Syndrome until parents became worried about the child's development. We believe that this policy is almost invariably wrong. Hippocrates first suggested that it was the doctor's job to understand the nature of the disease and to know its course. The doctor's ability to identify CORRECTLY that something is wrong and to tell the patient or his family about the possible consequences, raises the confidence in the doctor and allows him to be a more effective counsellor and friend to child and family. Further, early diagnosis may lead to effective treatment or amelioration of some potentially handicapping illnesses and/or secondary problems [such as contractures in Cerebral Palsy and secondary emotional disturbance in the family]. A service needs to provide the earliest possible identification of handicap."**

**Some doctors worry about the effect of a possible false diagnosis. Orthopaedic surgeon Akos Nevellos says that many of the children referred to him as "awkward" are perfectly normal:**

**"Are you going to tell the parents that their child is spastic? They'd crawl up the walls."**

**Others believe that wrongly diagnosing babies with transient disorders does them no harm. The important thing is to be sure to catch those children who ARE motor disordered in their first months or even weeks . Some doctors argue that it is a kindness to delay diagnosis. Nevellos states:**

**"You could argue that the longer parents are unaware that their child has Cerebral Palsy, the longer they are happy."**

**Yet children with other childhood problems are diagnosed.**

**O'Doherty [1977] contends:**

**"Parents are no more likely to be distressed by the need to watch the baby's neurodevelopmental progress than they are when the baby is kept under review because of a clicking hip or systolic murmur".**

**Indeed, to some parents diagnosis comes as a relief after the stress involved in the quest for this diagnosis:**

**"On our return home we were on a 'high' and we told everyone that she probably had Cerebral Palsy. We did not know what Cerebral Palsy was but it was something with a name and so it must have a cure."**

**Neither are parents who have to embark on a cycle of rote referral and self-referral happy until they receive the diagnosis. Many would assert that parents should be informed of any suspicion that their child is developing abnormally [Spain and Wigley, 1975], even if the Doctors are uncertain of the exact nature of the impairment [Quine and Pahl, 1987]. Indeed, in studies in the area of Mental Handicap, parents have been shown to be good assessors of their children's development. One such study [Coplan, 1982] :**

**"attempted to examine parental estimates of the developmental performance in a high-risk population. In this investigation 46 children [mean age 2 years and 8 months] were referred for developmental assessment. Each child underwent formal testing of language and**

intellectual development. Each child's mother was then asked to provide a subjective estimate of her child's level of function. The coefficient between maternal estimate and formal test results was found to be .85 [ $p < .001$ ]. This investigation established an important point. For high risk infants parental estimates of their child's developmental level can be accurate. This is particularly important because this is the group of children for whom paediatricians' own developmental estimates appear to be the weakest."

Not only were three out of the six families interviewed turned away by various doctors, but attempts were made to shift the focus of the problem onto either the child or the parents:

"I took him to a Paediatrician when he was eighteen months old specifically because he wasn't walking or doing things he should be. I was told he was just a lazy child, I should take him home and everything would be all right. So I took him home, told him he was lazy and all the rest and we continued from there."

"I opened the letter the doctor gave me for the physio and I couldn't believe it. He apologised for wasting her time. He said the child had no problem but the mother had - she was over-anxious and pushy and needed tea and sympathy."

Parents were caught up in a search for a doctor who would diagnose their child's problem:

"I remember going around here in [town] to various doctors to see if they could give me any help and no, they all said that they could find nothing wrong with the reflexes or anything."

**Still they could see their child's problem when compared to other children:**

**"My sister had a little girl at the same time, there was just three weeks in the difference and Mary would be on the phone to me and say: 'Is Sinead holding her rattle?' and telling me what Julie could do and I would say 'No, she just drops it'."**

**"First we compared her to a baby born a few weeks before her but when the gap became too great we started comparing her to a child born in the month when she was due. But that gap became huge too very soon."**

**Inability to get a diagnosis increased parent anxiety and sense of isolation:**

**"We bought and read so many 'Baby books' trying to find out what was wrong with her. We contacted the P.U. [premature baby unit] a couple of times but we were no longer their problem. We really were alone. The District Nurse called once but didn't really react to what I was saying. So much for the constant monitoring we were told she would get when she left hospital!"**

**Guralnick and Bennett [1987 p.15] consider that the strains induced by the search for a diagnosis are considerable and may have long-term implications for the child and his family:**

**"It is of course understandable that the parents' awareness of their child's handicap or even potential handicap and the often disruptive and stress-producing process that accompanies this awareness, may well interfere at least initially with the processes related to the formation of secure attachments [Battle, 1974, Waisbren, 1980]. It appears that excessive care-giving demands, lack of child responsiveness and any unusual behaviour patterns are closely associated with stress levels in parents [Beckman Bell, 1981]. However, just the existence of handicap seems certain to place that child and family at considerably greater risk for developing patterns that are not likely to be optimal for development."**

**Hewitt [1970 p.46] refers:**

**"to the feeling that parents have to fight for their children, the feeling that doctors [and other professionals] are opponents rather than allies, to be approached with a mixture of caution and militance."**

**The difficulty which many parents have in their relationship with professionals involved with their children can first be seen as far back as the period of pre-diagnosis and diagnosis. In many cases this period can be characterised by professional aloofness and insensitivity in their failure to give information and an increasing sense of isolation and distress on the part of the parents. In one case the Paediatrician who had been involved with the baby from the time of her very premature birth not only failed to diagnose the baby's condition but consistently refused to do so. He cast aspersions on other doctors who acknowledged that the child had problems and manipulated the**

**Health Board system to try to coerce the parents into passivity. From the start the parents found the doctor:**

**"cold and unresponsive. He answered all our questions with 'Well how do YOU think she is doing?'"**

**In the months after the baby was discharged from hospital the parents anxiety grew. They :**

**"really looked forward to our appointment with him in the New Year. We felt that as a Paediatrician he would immediately spot the problem and tell us how to make it better. Instead he told us that she was doing well, that any problems were due to her prematurity and to make another appointment to see him in a couple of months time."**

**Some weeks later, the worried parents consulted their G.P. about their concerns for their daughter:**

**"He was fantastic. He examined her and agreed that there seemed to be a problem. He said we should go back to [the Paediatrician] immediately. We did this and he still said there was no problem. Then at the next appointment I was more insistent. He said to me: 'You think that she has Cerebral Palsy, don't you?' I didn't even know what Cerebral Palsy was and said 'No, I don't' He said he was there at her birth and she suffered no lack of oxygen and she didn't have Cerebral Palsy. He said that he would refer her to a physiotherapist but it was a waste of resources."**

**Some month later the parents were desperate. They brought their child to the Out-patient Department of a large Children's Hospital in the Capital City. The child at this stage was:**

**"thirteen months old and no matter how much allowances we made there was still a problem. Three months off for prematurity and one, two, three, four, five months for trauma but it still was wrong. She had no head control, she couldn't sit, she couldn't crawl, her hands were fixed into fists and her arms were bent at the elbows."**

**There was some initial difficulty at the Hospital because the child did not have a letter of referral from a doctor. But by the time they left the Hospital they had a diagnosis of probable Cerebral Palsy and a referral to a specialist paediatrician. The parents then contacted their own Paediatrician and requested an immediate appointment which was not forthcoming. Despite this they went to their pre-arranged appointment some weeks later:**

**"expecting him to be pleased with this new insight into her problem. Instead we were met with a wall of coldness and rejection. He said he was present at her birth and she did not have Cerebral Palsy. He said that he was deeply upset that we would doubt that and go running to Dublin looking for a diagnosis from a junior doctor in an Out-patients department. He said that if we wanted a second opinion he would have arranged for one for us. He said that the doctor that we had been referred to was the Medical Director of a centre for Cerebral Palsy and had a vested interest in diagnosing children as having Cerebral Palsy. He said that if we took up that appointment we would be finished in [their home town]. He said he would withdraw the services of [the physiotherapist] and would make sure**

**that we wouldn't receive any other therapeutic services. This was a terrible time for us. We could either have a service at home but without knowing what was wrong with Rose or go to [clinic] and get a diagnosis and maybe a cure."**

**The refusal of the paediatrician in the above case to give a diagnosis is difficult to understand and for the first time we see a doctor using his position to exert pressure on parents to accept his opinion and reject the opinion of others whose views differed with his. He also threatened to withdraw services from the child if the parents did not comply with his wishes. This weapon of service withdrawal is one which we will see again as this study progresses.**

**In the case detailed above the diagnosis came as almost a relief but for many families it is a time of great trauma. However, a badly given diagnosis can cause great distress at a time when parents are already very vulnerable because of the pressure of their own concerns about the child. Woodburn [1977] writes:**

**"At whatever time the diagnosis is first discussed the occasion is critical for the social prognosis. Helpful information given with understanding, with acceptance of and concern for the parents' distress with ample time to allow them to assimilate the information and above all with the assurance of continuing help, may strongly affect their future ability to deal with the total problem."**

**The family mentioned at the beginning of this chapter were reasonably happy with the way in which they were given their child's**

diagnosis. The other families, however, received their diagnosis in a manner far removed from Woodburns ideal. One parent was tantalised and distressed by being given intimations that there was a problem without any limitations or name being put on this problem for quite some time:

"So I went to another family doctor and as soon as I walked in the door - it was around Christmas time - he just said: 'Well, you have a big problem on your hands, there's something wrong with this child.' And he wouldn't go into details as to what was wrong with him. He just said: 'You have problems' And so we got through that Christmas. I remember it was absolutely awful because I would go home and look at my child and wonder: what was going to happen to him? What's wrong with him? And I expected every day that his face would show something and he would become gawky and awful and whatever. So I was really frightened and very, very upset. So he was sent to [Voluntary Organisation] and they did an assessment on him, I suppose, and they didn't say anything. They just said: 'Go home, he seems to be all right'.--But a few weeks later I was called up again for an assessment and the doctor said that my son had Cerebral Palsy. I didn't even know what Cerebral Palsy was. So I went home, about eleven o'clock in the morning and finished off a half bottle of whiskey. I just did not know what to do. I was horrified and I was terrified."

Many elements of the above episode contributed to the intense distress suffered by the mother. She had to endure a fear filled Christmas after the initial crude diagnosis of a problem. This was followed by a reassurance from doctors unable or unwilling to give the diagnosis and finally, some weeks later, a diagnosis of Cerebral Palsy. All through this period, this single parent was offered no information and no support to assist her through this traumatic time. The cruelty

of this was heightened by the fact that the process went on for many months. However, the blow was felt just as keenly by the other families who were given the diagnosis without any attempt to prepare them for the news:

"the doctor said: 'Well, you know that your child is mentally and physically handicapped' and that was the beginning and the end of the conversation."

Writing in Care of the Handicapped Child, a Festschrift for Ronald MacKeith, Freeman and Pearson [1978 p.36] state that:

"The need to understand what has happened to their child is a major source of the emotional tensions experienced by parents. Their questions, both spoken and unspoken, regarding what the condition is, why it has occurred, how it can be treated, and what the future holds, must be answered before time and effort are expended on analysing and interpreting the parents' attitudes and feelings [Dybwad 1966]. As MacKeith [1973] has stated: Until their anxieties are [to some extent] dealt with by full assessment and explanation their child is 'not a person but a question mark'. This explanation and assessment should be given as soon as possible [Drillen and Wilkinson, 1964, D'Arcy, 1968, Berg et al, 1969, Burton, 1965, Carr, 1975, Pueschel and Murphy, 1976]... Parents should be encouraged to clarify and verbalise their concerns, and time needs to be provided to deal with these."

Five of the six families in this study were given a diagnosis without compassion, sympathy or empathy and this was followed in all cases by a total lack of support, information, and counselling causing great anxiety and concern. This lack of information can have a severe

**impact, even on a mother who, as a nurse, had a medical education. Left without information, she picked the worst possible prognosis for her daughter:**

**"he referred me to a Paediatrician and he told me that she had Cerebral Palsy and when he said Cerebral Palsy, I don't think I had ever heard the words before and I'd read lots of medical books and everything else and so I knew a fair bit but I'd never read - so I came home and looked it up in the books and decided that she was going to be severely mentally and physically handicapped."**

**Another informant says:**

**"I didn't find the services were of great help after the diagnosis, we were just told that he had Cerebral Palsy and we were told that he would have therapy for it and that was all. There was no one to explain what it meant or anything else, we just got our own books and found out what the diagnosis of Cerebral Palsy meant."**

**Not only was no information given in any of the six cases but in one situation where the child's mother asked for some sympathetic support, she was treated with cold disregard:**

**"I remember looking at the clock and I could hear outside in the canteen they were serving lunch and she was looking at the clock as well. I said: 'You know it's all right while I am alive but the big fear is what will happen when I die?' She stood up from the desk and said very efficiently: 'There are plenty of homes and they are getting better all the time' So out we went."**

**Another example of the lack of professional understanding for the parents during this time can be seen in the often casual way in which the doctors will diagnose an additional mental handicap. The freedom with which they give this diagnosis contrasts with the reticence of many doctors to give the initial diagnosis of Cerebral Palsy. Whether this is due to ignorance on the part of the doctors who assume that the term handicap is a generic one is unclear. But parents find this diagnosis particularly difficult as it can conflict with what they already know about their child:**

**"When Martin was diagnosed, the first doctor said he was mentally and physically retarded. I just remember feeling very angry that she should diagnose that he was mentally retarded because I knew from his reactions up to this that he seemed to have the normal reactions of one year old child."**

**Parents are also angered that any intellectual assessments that their child might have to undergo may be done under conditions prejudicial to a young child's performance. Psychological assessments of children with disabilities have traditionally taken place in Dublin which can mean that a child might have travelled five or six hours before being tested in unfamiliar surroundings. It is therefore not surprising that many parents resent and reject the additional diagnosis of mental handicap:**

**"We were told by the [specialist clinic] when Stephen was about two that Stephen was mentally handicapped and that he would be going to a special school which we ignored. We knew that the child was quite intelligent**

**and they had never seen him before in [specialist clinic], he was tired after five hours travelling and it wasn't fair to make a diagnosis under those circumstances."**

**Common problems run through all the case studies when looking at the manner in which the children were diagnosed as having Cerebral Palsy. Several parents had difficulty in getting a diagnosis at all despite their own conviction that their child's problems were very obvious. It is noteworthy that in these cases the doctors who eventually gave the diagnosis did so almost immediately upon seeing the child, vindicating the parents belief that the indications of the presence of a disorder were very apparent:**

**"we went for a second opinion to another paediatrician who the minute he saw her he said: 'She's got Cerebral Palsy'".**

**"from the minute he began to examine her his whole attitude changed. He agreed she had a problem and arranged for some tests. As soon as they were done he said he thought she had Cerebral Palsy."**

**The question arises as to why the other doctors in these cases did not diagnose the children's problem. One parent, who was dealing with a paediatrician who attended the child's birth, believes that his refusal to give or accept a diagnosis was based - at least in part, on a fear of litigation. But in the other cases the difficulty in getting a diagnosis is hard to understand. Equally hard to understand is the fact that none**

of the six families received any information, counselling or support at the time of diagnosis. Information is crucial because none of the six families had any knowledge of Cerebral Palsy prior to diagnosis and therefore could not construct any framework for their child's future to replace the one that the diagnosis had undone. The need for information and support is by now well established and its absence can have disastrous results for the child and his family. Bavin [1974 p.13] documents the process of mourning, isolation and desolation which many parents go through while making the adjustment to the fact that their child has a disability. And he states:

**"Without skilled help most distressed parents will tend to an adjustment which reduces their distress, but at the cost of distorting their relationship with the handicapped child and the rest of the family."**

The physical handicap can itself work against the establishment of normal family relationships and induce stress. Gualnick and Bennett [1987 p.18] writes:

**"Effective parenting is not an easy task even with healthy, normally developing children under ideal conditions. When the children's signalling, feedback and affective systems are not as intact as is common for many children with handicaps or those at risk, it is not difficult to realise how readily patterns that are not optimal for development can arise."**

Early and correct diagnosis are important to optimise the development of positive family relationships. And a bald statement of

what a doctor perceives to be fact is not sufficient. Without detailed explanation of the handicap and its implications parents may not have the knowledge necessary to overcome some of the difficulties which they can face. MaGee and Sutton [1989 p.2] explain:

"Movement and motor functions are intimately involved in children's psychological development, in interaction with the social and material world. From the children's viewpoint, motor disorder impairs, distorts or even in some cases altogether prevents the ability to interact with the world in ways that are predictable, reliable and contingent. Such children cannot change their position in space or their perspective, cannot direct their gaze or avert it, cannot reach, point, manipulate, fetch, cannot initiate and maintain eye contact, smile, develop appropriate facial expressions or look or sound appealing to adults with the same facility as they would have done without the motor disorder. Correspondingly, adults who care for children may have to do so without the familiar cues [vocal, physiomic, postural, practical] which are integral to the normal interactive process. Indeed, responses can be actively misleading, for example, the cuddled infant may remain floppy or arch its back, whilst spontaneous attempts to help or initiate interaction appropriate to normal development can lead to frustration and failure for adults and child alike. The normal cognitive and emotional mechanism in the adult child dyad do not work as either the adult or child participants might reasonably expect. All the hard work and devotion expended may result in limited or negative gains. The normal interactive cycle may be poorly established, diverted or even grind to a halt in a deleterious cycle....."

None of the families in this study received any professional support at the crucial time of diagnosis. Parents need a correct, timely diagnosis with all the support necessary to enable the parents to face the future feeling that they have in themselves the resources to control it. That

**the families coped so well is a tribute to their own resourcefulness and to the support received from family and friends. However a recognition must be developed of the need to put counselling and support services in place and the price that can be paid by some families if these do not exist. Woodburn [1977] states:**

**"It is everyone's loss when, for the want of early, adequate and continued help to parents, the unity of the marriage is destroyed, siblings develop behaviour disorders or vast sums are spent on institutional care, because society denies parents the kind of resources that enable them to keep the child at home. Parents need the same kind of help when subsequent major decisions or changes arise. If throughout parents are offered an attitude of concern, support with practical difficulties, opportunities to ask questions and have the feeling that the professional staff are their allies, they will be enabled to act constructively."**

**None of the parents in this part of the study expected or were prepared for their baby to have a handicap. None had any experience of children with disabilities. As gradually they realised that their babies were not developing as they should, they looked to the medical profession for explanations, information and support. In most cases they were initially rebuffed and rejected which served to increase their worry and distress. Diagnosis, when it came, was abrupt and dogmatic. Without exception, parents were then left in a condition of considerable confusion without any of the information or support which they needed to comprehend the implications of the diagnosis and to construct a framework for the future for themselves, their handicapped children and their siblings. Information is vital, but**

**equally important is that it should be imparted in the correct way.**

**Freeman and Pearson [1978 p.36] wrote:**

**"The parents may remember little of the factual information given to them following the initial shock of diagnosis but they are typically impressed by the attitude of the informant [Deacy 1968, Berg et al 1969, Pueschal and Murphy 1976]. The need for compassionate empathic [ rather than sympathetic ] understanding, sensitive personalised concern and patience on the part of the counsellor is probably greatest immediately after diagnosis. The counsellor's ability to communicate these attitudes will largely determine whether the necessary degree of mutual confidence, trust and respect can develop [ Irvin et al 1976 ]."**

#### **Summary Conclusion: Diagnosis.**

**The time at which a child is diagnosed as having a disability is a critical one for both the child and her family. The diagnosis should be given sensitively and should be followed by appropriate information and counselling. However, most of the parents interviewed for the purpose of this study experienced negativity, rejection, non-disclosure and wrong diagnosis and this caused frustration and varying degrees of trauma. The initial contact with a professional also establishes the foundation of the parent/professional relationship**

**which is essential to the physical and mental well-being of the disabled child and his family. A badly handled diagnosis undermines this relationship and can leave parents more susceptible to seeking an alternative to what they have experienced.**

## **THERAPEUTIC PROVISION**

**The second area of tension found in the material is manifest in the question of therapeutic provision following diagnosis. The provision of early therapeutic provision appears to be another stage which causes parents to experience frustration and a sense of alienation from professionals. They may be forced to watch their child deteriorating or failing to achieve development which parents believe would be possible with the correct remediation. The parents themselves want to do something to help their child but do not know what to do. The services, on the other hand, offer meaningless and sometimes contradictory advice, providing what the parents perceive to be inadequate and insufficient therapy and sometimes withdrawing provision altogether if parents are thought to disagree with or defy the professionals. In some cases, it will be shown, therapy is performed so insensitively as to cause trauma to the parent and the child.**

**When their children are diagnosed as having Cerebral Palsy, parents assume they will be immediately brought into a system of therapeutic care which will serve to maximise their physical potential. It has been established as far back as the Warnock Report [1978] that the**

attitudes of parents or care-givers to a disabled child play a crucial part in the optimal development of the child. If parents are positive, accepting and willing to work towards the habilitation of their child it stands to the child's future development. But the parents interviewed for the purposes of this study were unable to develop this sense of optimism due to the frustration of their efforts to obtain the therapy which they considered essential to their child's development. Their belief in the importance of early therapy is supported by many authorities. McGee [1989] believes that:

**"The age of two is too late because you've missed the period of cerebral plasticity. At that stage you can reallocate some missing parts of the brain while the child is still gaining brain cells."**

**This belief is echoed by the Bobaths - long the standard bearers in the treatment of Cerebral Palsy in the British Isles [Bobath 1984 p.13] :**

**"In most cases very early treatment will give quicker and better results because the baby does not yet show much abnormality and therefore has little experience of abnormal movements. Futhermore, because treatment and handling are easier for the mother and the therapist, the mother can be more easily be instructed and trained in the best way of handling the baby all day long, dressing, carrying, feeding, washing etc. Her involvement in management and treatment helps in establishing a good mother-child relationship and also gives her support and encouragement. It helps to prevent over-protection, as well as rejection. In fact, advice and training of the mother enables her to obtain the most normal active movements of the baby in response to her handling [Finnie 1974]. She will learn to avoid abrupt handling, which can produce fear and**

**discomfort in the infant and undue stretch of spastic muscles."**

**With such overwhelming benefit accruing from early therapeutic intervention, it is obvious that parents would expect that their child would start therapy immediately after diagnosis. Yet this did not necessarily happen:**

**".... it was only basic management at home and we weren't sent for physio anywhere which was amazing."**

**"We would bring him out to the [ clinic ] for physiotherapy and this turned out initially to be once a week for half an hour and as time went on it changed from that to every three or six months."**

**and most astoundingly:**

**"When she was diagnosed no treatment or no therapy was ordered..... and when I did go back and asked: 'Do you think she needs therapy?' and he said 'If you like I will refer you to a physiotherapist' and I went to her and she told me to buy an Army exercise book - that there was a specific section there, that I could follow that.... it was totally ineffective, it was really stupid."**

**This was the stage in the children's lives that they would have derived most benefit from therapy. Davd Scrutton, Superintendent Physiotherapist at Guy's Hospital wrote in 1984:**

**"whilst not decrying the need for treatment of older children or adults, most therapists favour early treatment and there is general agreement that the younger the child the greater the effect of the treatment. There are a number of reasons for this: [1] massive myelination is occurring. It is probably easier to form correct movement habits before incorrect ones are established. [2] Most parents expect to devote a large proportion of their time to a baby during its first two years of life and so it is easier and more realistic to involve them in treatment. [3] Treatment does not interfere with the education and social life of the child. [4] It is a time when parents need close contact with someone who understands their problems in a constructive manner, gives them something positive to do and can help them to find out about and understand their child's emerging difficulties." [p.13]**

**At this crucial point in their child's lives the families in this part of the study were not receiving any of the benefits outlined above. Indeed in the most extreme case the parents were forced to watch while their child deteriorated physically while they struggled to obtain physiotherapy for her:**

**"I remember being on the phone and being absolutely distraught trying to get a referral to get something done because she was getting worse - from a child who looked kind of normal, then the spasticity, the crossing of the ankles and the tightness was getting worse and worse. She was about three."**

**While in some cases the child was receiving no physiotherapy at all, in other cases the child was getting therapy but it was carried out with such insensitivity to serve only to cause trauma to the child and his parents:**

**"We didn't find the therapy very effective because it was just half-an-hour and he was going into this lady and really it was just a crying session for the half an hour that we were there - a screaming session. And there was no - they didn't give him the chance to even become aware of where he was or anything, they just took him in for half - an hour screaming and out again. It wasn't effective because of that. They couldn't see what he could do and I often found they were quite annoyed with the screaming so they didn't show us what to do."**

**For any young child to be taken from its mother by a stranger and have his limbs manipulated would be a frightening experience. For a child with Cerebral Palsy, it would be terrifying. Finnie [1974 p.5] explains that all such a child can do:**

**"is to cry and become stiff and frightened. If he is the 'floppy' type of child he will have to be supported and held everywhere or he will fall. Because of this we must handle a Cerebral Palsied child slowly and give him a chance to make his own adjustment as we move him, supporting him where necessary, but waiting and giving him time to do whatever he possibly can by himself. One should try at all times to enlist the child's cooperation."**

**This concern for the child was not experienced by some of the families in this study:**

**"The treatment was to include occupational therapy and physiotherapy and I don't think it helped him at all. For all the trouble it took to get there we only had thirty to forty minutes every week and that certainly wasn't sufficient for a child who had problems and he didn't get on with the physiotherapist who threatened him with me and said 'Your mother will go out of the**

room unless ..... you do such and such`. She and I had a big row about this sort of thing and the help we were getting out there so it really didn't do much good and it didn't help me to cope with the child either."

Two of the six children in the study turned to an `alternative' therapy - the Doman-Delacatto or Philadelphia method. Others considered this method but rejected it for various reasons:

"I read about that Doman method, that's where you turn the child upside down..... I read about them but I never wrote to them or anything."

"The first time we thought of an alternative therapy was the Philadelphia Insitute and we had written there and enquired about it. When I discussed with Martin's psychologist she was totally against it. She thought that because he was a bright child it could have bad effects on him mentally and he'd always been such a sociable child that she advised that maybe there was some other method we could think of. "I didn't do any of that. I didn't know a lot about it but what I did know I thought it was too complicated and I wouldn't be able to manage it."

The two families who did embark on the Doman-Delacatto method were very pleased with the results that they achieved:

"And I felt the Doman-Delacatto method helped Ben greatly, I really did, I really felt I'd made a start. From a child who would sit in the middle of the floor doing nothing except cry, we managed to get a few words out of him and he started to move around and his life changed and I was really impressed by it."

**"Doman was probably the most significant period in Roses life. She did very well physically. Plus, she was physically tired for the first time in her life and so she started to sleep better. And because she had such close contact with so many people during this time she also became more sociable."**

**The Doman -Delacatto method is an extremely demanding one on both the child and his or her family involving teams of volunteer helpers working with the child for hours each day. It was this that forced one family to discontinue the therapy:**

**"It was very, very difficult to do and and it took a lot of organising and it needed a very, very steady home life which I didn't have."**

**For the other child the programme came to an end as the child entered the school system:**

**"As Rose started pre-school the Doman programme just went into a natural wind-down."**

**The opposition encountered by both families when they embarked on the Doman-Delacatto programme was intense and the price they paid for defying the professionals was severe:**

**"I told them about it in [clinic] and they were most unhappy about it and they told me that if I was to do that, that I could not attend them because Ben was doing the Doman-Delacatto method. I remember I was very upset because I thought they were the only people I could turn to and if I did the Doman-Delacatto method I was leaving myself totally open - there was no one I could turn to and begged them - would they not even see him on a once a month basis but they said 'No'. In the meantime someone else had heard about me doing it and sent me up to some priest in [voluntary organisation] to tell me that it was a vile treatment and it turned out angry and vicious children and all the rest. But against all this I went ahead and did it anyway."**

**"[Doctor] in the [clinic] said that our decision was totally unacceptable and we couldn't attend there again until we had come to our senses."**

**The second family had already had local services withdrawn from their child because of their decision to attend the above mentioned clinic in their search for a diagnosis. Thus, by the time this severely handicapped child was three years old she had suffered withdrawal of services twice because of the parents perceived unwillingness to conform to the wishes of the professionals.**

**Another family in this study experienced service withdrawal at an early stage in the child's life - not for attempting an 'alternative' therapy outside the system but rather for trying to maximise therapy sessions within the system:**

**"So, in order to get an extra little bit of therapy for our child, we started going to [physiotherapist employed by a voluntary organisation] in the alternate week to**

**{hospital physiotherapist}. So the Hospital showed us the door, they said it was because we were going to [physiotherapist employed by a voluntary organisation]."**

**The readiness with which Paediatricians withdraw State funded services from handicapped children will be highlighted again when discussing the reactions of professionals to parents introducing their children to Conductive Education.**

**Thus, several years after the initial - often traumatic - diagnosis, the parents of the six children were in a condition of confusion and frustration and three of the six families had already had their children expelled from the system. Not only is the system failing the children and their families during this critically important period but once again it is working against itself - sowing seeds--for--further disaffection and defection. Taft [1981 p.74] a child neurologist who has published extensively on the importance of early intervention - states that:**

**"Clinical observation has shown me that intervention programmes have the following benefits for motor-disordered children and their families: [1] better parent-child relationships; [2] child more strongly motivated to try new motor tasks; [3] less parental 'shopping'; [4] quicker and less painful adaption by parents to child's handicaps; and [5] a happier child. Some people might consider these results insignificant for, say, a child who cannot walk independently. I disagree! Growing up without depression, well-motivated and socially competent in spite of a serious handicap, meets my criteria for a positive outcome."**

Parents are continually frustrated in their efforts to receive those services which they believe are essential to the development of their child. Indeed Sunman [1984] stated that the most distressing experiences which parents of children with disabilities suffered were not directly related to their child's condition, but were, in fact, related to their experiences with the professionals who were ostensibly there to help them.

Parents are not just willing but are desperate to devote whatever time and effort is necessary to facilitate their child's development but this resource is left unexploited, leaving parents feeling rebuffed and angry. Parents who have deviated from the professionals' 'norms' were being severely punished and those who stayed within the system were being asked to do things which they felt ill-equipped and ill-informed to do. A Medical Director said to one mother;

**"Well, you know it is all up to yourself, Mrs Davis, you've got to do everything.' And I said 'Do I have to be a speech therapist, occupational therapist, physiotherapist, and a teacher?' 'Yes you do.' he said. So that was his answer. It was all back to me when I complained that she wasn't getting enough of any of these. It was all up to me to do it at home. And they never taught us to do it and they would never say 'Come on in and we'll show you how to do it.' And then if you needed anything it was very hard to get it. They would tell you six months later that you need this, say, for a high chair. I always had Sinead in an ordinary high chair with no addition and she really should have had an insert but none of this happened, you know. And she got, the big thing, she got a wheelchair when she was six and again she got this wheelchair which she**

**has now when she was six [now aged eleven]. So any chance she had of wheeling herself was gone by the board - the thing was just too big - you know? But they just don't suit the child. They have a load of wheelchairs and they are cheap and here's one, without ever suiting the child or the family or what the house is like or anything."**

**Many parents thought that when they had finally won the battle to obtain a diagnosis of their child's condition the war was over and that they could get on with the business of remediating this condition. But all found that the battle for adequate therapeutic services to be an equally difficult one. None found the level or quality of provision to be acceptable:**

**"the normal going into the hospital every three weeks for half an hour was a waste of her time and a waste of my time."**

**and parents continued to feel that the system was not serving their or their child's best interests and that every thing must be fought for.**

### **Summary Conclusion: Therapeutic Provision.**

**An adequate therapeutic service would deliver optimal therapeutic care to remediate the child's disability and educate and reassure the parents. The families in this study, however, received a standard of provision which left them feeling desperate and frustrated. Their own willingness to help their children was not harnessed and their children's potential was seen by them to be left unexploited.**

**The insensitive manner in which some therapists treated children and their parents and the freedom with which paediatricians withdrew State services from children whose parents were perceived to be difficult or non-conforming caused trauma and distress to parents. All this served to further alienate parents from professionals and driving them closer to systems that might be more likely to meet their needs and those of their children.**

### **SCHOOLING**

**The third area identified as one around which tension and dissatisfaction may be experienced by families with a disabled child is that of schooling.**

**Schooling represents another crucial phase in the development and socialisation of the child with disabilities. Evidence from the interviews indicates that while parents may not have experienced the same level of stress as at the earlier stages, they nevertheless felt frustrated by the lack of suitable procedures and structures. The process of schooling is characterised by a sense of drift into**

**inadequate facilities with no proper assessment. Parents whose children attend 'special schools' felt that the children were not motivated or stretched academically and those whose children attend mainstream schools felt that they were neglected in terms of ancillary care and support. Parents have to work harder - they have to cope with additional difficulties such as transport and also work to compensate for the deficiencies in provision.**

**The time at which a child with a disability enters the school system can be another time of crisis for parents. Once again it can be a time characterised by no advice or bad advice and often placements which the parents felt were inappropriate for their children.**

**Five of the six children studied for the purpose of this research received some form of pre-schooling. One child of the six attended two pre-school facilities. The first was a very small special school with a staff-child ratio of 2:1. This placement was very successful but her parents felt that the leap from such a protected environment to a class in a National School would be too big an adjustment so they decided that she should spend a year in a Montessori school. This, however, turned out to be very unsuccessful:**

**"the teacher was young and didn't know what to make of Rose at all even though this school was on the recommended list we got from [voluntary organisation]. So Rose used to cry all the time which drove the teacher crazy and she used to put Rose into the hall on her own as a punishment and that made the child so much worse."**

**The parents decided to send their daughter to another school where they felt that the teacher would be better able to cope and that their daughter would be happier. The professional advice which the parents received at this stage still causes them upset as they feel that it could have irreparably damaged their child's chances of settling into any school in the future and it caused both the mother and her child to suffer a very traumatic year.**

**"I asked the child psychologist about moving Rose to the other school but she said 'Absolutely not!' She said she was just being manipulative and if we moved her she would have won and then we would never get her settled at any school. So for the whole year Rose cried from once she got up and all through the school day and then when she got home about the next day. I don't know how we got through that year And all this was on the advice of the psychologist who never left her office, she never even bothered to go down to the school to see how awful it was and how the child was suffering.**

**The other child who went to a 'normal' pre-school did so on the advice of a psychologist and the experience was a positive one:**

**"So we sent her to pre-school which I think was very good, a nursery teacher ran it. It was a small one in the village and she was very good with her. She was an independent child, she was never that attached and was happy to go to other people."**

**Three of the other children attended 'special' pre-school facilities. One mother was happy with the situation and two were very unhappy. In the two cases where the mothers were unhappy, their dissatisfaction stemmed from the fact that they felt that the children had been**

**inappropriately placed in services for mentally handicapped children and that they were therefore not receiving the appropriate stimulation:**

**"You saw so many children in that school, that pre-school place and they were all so severely handicapped. It seemed like a place you just put your kid every day just to get them out of the way..... That place depressed me greatly and I took him out of there."**

**The lengths to which parents are willing to go in order to maximise their child's opportunities can be exemplified by the family which moved house to enable their child to attend a recommended pre-school only to be disappointed with the placement:**

**"When Martin was two, the physio in the [clinic] suggested that we should see a paediatric doctor and she suggested at the time that we should think about sending Martin to pre-school. But as there wasn't a pre-school where we were, we moved up, we moved house so we should be within reasonable distance of getting him there, and he started when he was three in pre-school. And it was where they had an awful lot of mentally handicapped children and it really wasn't of benefit to him at all. He only stayed there three months."**

**In these last two examples we again see children who are assumed to be and are treated as being mentally handicapped simply because they have a physical handicap. And because this conflicts with the parents' own knowledge of their child's ability it causes unnecessary parental anxiety and encourages a lack of faith in those professionals**

upon whom the parents need to depend. And given that none of the children received an adequate pre-school educational assessment, it is not surprising that so many of them found pre-schooling to be a negative and unsatisfying experience. Parents had no sense of being involved in their child's placements and were often advised into placements which they later felt were inappropriate, and in one case, persuaded to stay in a placement where the parents felt the child was being psychologically damaged.

The situation did not improve as the children moved into primary schooling. Again this period is characterised by a lack of assessment, counselling, support, advice and a feeling of drifting into a service. And in one case there was the need to reject what the parents felt was a wrong diagnosis of a mental handicap:

**"we were told by the [clinic] when Stephen was about two that Stephen was mentally handicapped and he would be going to a special school which we ignored.... And he went to a normal school where he is doing fine. We hoped he would be able to fit in as well as he could. And he does."**

The two children who received special school facility had been receiving therapy services in clinics attached to those schools. Parents seem unaware of being involved in any decision making process preceding their children entering the 'special' school system:

**"It was this doctor who arranged the placement in the special school."**

**"Well, with schooling I suppose the fact that she was in the clinic from aged two and a half and they had a special school there, that she went there as a matter of course. And I suppose we were lucky enough that we had it in one sense, but then we never thought about mainstream school because of that being there."**

**Both these families experienced difficulties with the 'special' schools because they felt that the children were too protected and that too little was expected from them academically:**

**"I sometimes wonder now whether it would be better for a child like Sinead to be having to muck in with others and more would be expected of her. I always find they don't have very high expectations of the children, so the children don't perform. I mean, we have high expectations at home, she has to be the same as the others. They make so many allowances, I think, it's probably not a good idea because the children grow into adults and live in the real world and nobody is going to make allowances for them."**

**This mothers instincts are supported by Mitchell [1978 p.62] who asserts:**

**"Segregation in special schools is favoured by some people who have the interests of the handicapped at heart and who honestly believe that they are happier living with their own kind, protected from the rejection, ridicule and indifference they may meet in the outside world. However, unless the child is going to spend the rest of his life in a closed community, with all the withering of abilities and personality that this implies, he will have to emerge some time and the longer this is postponed the greater will be the impact and the difficulty of adjustment."**

**The mother of the other child in the 'special' school system was greatly distressed by the low academic expectations of the child:**

**"At the time and from what the doctor had said I thought he would do the normal curriculum in the school and I thought that he would have whatever physiotherapy was necessary for him to improve. But as time went on we found that the school was not at all satisfactory, just doing very basic playgroup things with him and this was when he was five and six. And he was mentally alert but it was just the minimum of education he was getting. It was a constant, every week, going in to find out why he wasn't doing his reading, why he wasn't doing his writing. So what we did was, we have a child a year younger so we started teaching him from the other child's books. So it was only when Martin went in and started telling them that his mammy was doing his brother's school work with him that they started doing anything with him at all. But it still wasn't satisfactory. It just meant going in constantly questioning why he wasn't doing this, that or the other. And really the only reaction we ever got was: 'Why, why push him so much, why don't you let him enjoy himself?' But Martin, being a bright child, all he was doing was complaining that his brother was getting new books and he was getting no new books. And his brother was doing new maths and he was doing no new maths."**

**The frustration experienced by this child and his family led them to make the decision to transfer him to a National School:**

**"Two years ago we decided to send him into National School and it was fantastic for him. We just tried for the first year and he learned so much, emotionally, every way. He just thrived on the whole thing, there were no problems at all, none whatsoever. He went into a class of thirty-five children and just got on with it like the others...And he did two years there in the one year and really did fantastic."**

**None of the children who went straight into mainstream school had the option of a 'special' school facility in their area unless they were to attend a school for the mentally handicapped. Once again with these children there is a sense of drifting rather than decision making:**

**"And from pre-school, we just decided - I don't know who decided - the psychologist, I suppose, they decided we would try her in normal school and see how it goes. But special school in [city] meant bringing her into [voluntary organisation] which was for mentally handicapped and that was cruel. We always thought she was reasonably intelligent."**

**Lack of support structures forced one parent into the unenviable situation of having to 'hawk' photographs of her daughter around various National Schools until at the fifth attempt she found one to accept her:**

**"Three had various reasons for turning her down - overcrowding, lack of resources, etc. ....but the fourth really upset me. She told me that there were schools for children 'like that'. When I asked her where, she said [voluntary organisation]. I said that was for mentally handicapped children and she said that it was all the same thing and that 'children like that' should be educated together."**

**The children who attended National Schools vary in severity of disability from mild to severe. In no case has any support structure been put into the schools to assist either the child or his teachers. They are left, with their families, to muddle through as best they can:**

**"the sister who was only a year older was expected to toilet her and I think, looking back, I shouldn't have allowed that to happen, because it was too much of a burden and she was only eighteen months older."**

**"We live near the school so I go in myself. I go in three or four times a day in case he needs any help."**

**"There was no help at all in the school for the first three years. The teachers fed her her lunch and toileted her and gave up their breaks to help her in the playground. And that was with thirty-five other children in the class. In the fourth year we got a teacher's assistant from F.A.S. But when this finished after one year we had to work with a politician for months to get a Ministerial order to get it extended for another year. And it is still year to year, which is very stressful as she would probably have to leave the school and her friends if we lost this support."**

**Despite the lack of support for any of the children attending National Schools, the parents are unified in their conviction that the children are where they should be, and all pay tribute to the teachers and the other children in the schools:**

**"Ben goes to a normal school. He is the only physically handicapped child in his school and I feel he has a great deal to cope with and has done so very well with an immense amount of help, mainly from his colleagues."**

**"the other kids are wonderful and his teacher is excellent, she has wonderful interest in him, she is very helpful."**

**"It would take dynamite to shift Rose from that school. It stretches her academically and she is in an able-bodied environment, just as she will have to live in an able-bodied world. And I believe that the other children benefit from her presence."**

#### **Summary Conclusion: Schooling.**

**Whether a child with a disability enters a 'special' or mainstream school system, parents need to feel that their child's individual needs have been identified and responded to. However, the above section shows that parents whose children received 'special' schooling feel that their children are undervalued and unchallenged. And where a child with a disability attends a mainstream school the child, the family and the school are left without necessary support structures. Both situations serve to cause stress and trauma to the parents. Parents already feel that their child is disregarded by the medical care system. To see them undervalued or ignored by the educational system, serves to increase parental alienation from all that is on offer in this country.**

## **PETO INSTITUTE**

The previous sections have established that at critical times in the lives of the disabled children the provision available to them caused varying degrees of frustration and anxiety to their parents. This resulted in an alienation of the parents from the professionals with whom they were dealing. Parents had no sense of involvement with the professionals and no sense that the system was working in what they perceived to be the best interests of their child. The argument concerns why it is that parents then choose an extreme form of therapy for their children in terms of travelling to an alien country with obvious language and other difficulties for a brief assessment initially and then for longer stays ranging from one month to three years.

The evidence would seem to indicate that for the first time parents no longer experienced feelings of frustration at their own and the professionals' inadequacies but rather an offer of total acceptance on behalf of professionals whose provision matched their own instinctive and often inarticulated expectations. As well as this body of evidence, there is also evidenced the reaction of professionals at home to what they perceive as magical, unproven, overly selective and too difficult for the children. This reaction, it will be shown, caused the parents to experience further frustration.

Cummins [1988 preface] characterises the attraction of parents to therapies outside the conventional as the lure of 'magical therapies':

**"Perhaps more than any other area of scientific endeavour, special education is beset with magical thinking. And it is not difficult to see why. The parents of disabled children fervently wish their child to be as normal as possible. In their desire to achieve this end they seek advice from professionals. Such advice, however, may not tell them what they wanted to hear. They are not seeking a diagnosis which simply depicts their child a deviant, or paternalistic advice that they should 'make the best of it' They want to DO something to make their child more normal. They want information, in particular, they want information concerning intervention programmes They have a strong need to communicate, to talk about their child, not in terms of what he or she cannot do, but what he or she can do or might be able to do given the right circumstances. Unfortunately professionals too often fail to meet this need. Resulting from this failure parents often feel drawn to 'alternate' forms of therapy. This transition to an unconventional mode of treatment will often transport parents into a magical world. It may be a world without negativity, where the child is not only accepted for what he or she can do but is also given the promise of becoming 'normal' or even 'superior' to other children provided that the new programme is adhered to. The parents may also encounter, perhaps for the first time, an environment where they are able to meet other parents with whom to share their experiences."**

**But for most parents, turning to an 'alternative' therapy has little to do with 'magical thinking' and more to do with deep-seated trauma, frustration and isolation. At the point at which they made the decision to take their children to the Andras Peto Institute in Budapest, the parents in this study had basic questions which were still unanswered. Their children were receiving a level of therapeutic care which they considered to be gravely inadequate, they had ceased seeing professionals as working in their child's best interests and they**

were frustrated by the negativity which they seemed to encounter continually and, they often felt, unnecessarily.

Cummins' book The Neurologically Impaired Child: Doman-Delacato Techniques Reappraised [1988] seeks to challenge the basis of the Doman-Delacato method of treating brain-injured children. Yet much of what he accepts to be the appeal of this therapy is valid when looking at why so many parents sought help for their children from the Peto Institute:

"There is no practical use to the parent or child of a complex and definitive medical diagnosis unaccompanied by useful positive information in relation to habilitation. When frightening or unduly pessimistic views of the child's future are provided or when parents are not helped to deal with their feelings, it is hardly surprising that they flee to unorthodox therapies to seek more comforting and optimistic advice..For the first time parents may be in receipt of advice they can understand and which promises a positive outcome for their child. In addition, their active role in the habilitative process is encouraged.... There is no doubt if such energy could be channelled into conventional forms of therapy the child would be far better off. But it is not, and in such situations the professional system of care has failed." p.19.

Certainly, the parents in this study felt that the professional system of care had failed. Their concerns were still unresolved and the vital resource [Warnock Report 1978] of their own desire to work for their children's rehabilitation had been left totally unexploited. They also felt isolated and without information.

Although Andras Peto had developed his method in the 1940s and individual therapists had been introducing and adapting it in the West since the 1960s, the catalyst for the upsurge in interest was the B.B.C. documentary 'Standing Up For Joe' screened in April 1986. Although the documentary finished with the statement that the Institute's doors were now closed to Western applicants, the B.B.C./Hungarian Embassy received eleven thousand enquiries on foot of the programme. This programme was the first introduction which five of the six families had to Conductive Education and one of them was on their way the following day:

"I first heard of the Peto Institute, I think it was the April or May of 1986 and there was a programme on the B.B.C. television about the Horsely family who arrived there with their son Joe. And when I heard it I was very happy. I saw the programme at 8 o' clock that evening and the next day I was on my way. I reacted this way because when someone needs help you will do anything. And it sounded like an idea I couldn't turn my back on without sussing out a little further."

This feeling that the Peto Institute offered something which had to be investigated was a common one and was born out of a disillusionment with what was being received at home:

"And from just reading about the Peto method we thought it's certainly worth a try since anything here hadn't been any good for him. There was nothing here that was going to work, so it was worth trying out something else."

**"I always felt people were very negative, therapists were very negative, it used to annoy me. I was always kind of positive because I felt, you know, she was very much with it and I felt there was a great chance that she would lead a normal happy life. I just thought [Standing Up For Joe] was absolutely fantastic, sort of an answer to our prayers."**

**"I read about Budapest in the papers when he was young, we were grasping at straws at that stage and we were willing to go anywhere or do anything that would benefit the child."**

**"I think I saw that programme "Standing up for Joe" and of course we looked at it and the way he responded and we thought this was really wonderful.... I felt it was something I should do, and I would go anyway."**

**"The programme was totally amazing. They were focusing on what the child could do and not what they couldn't do. They believed that the child could do things for himself."**

**Before admission to the Peto Institute children must undergo a brief assessment of suitability. The youngest child in this study was able to avail of an assessment facility in Dungannon, Co. Tyrone which did not exist in the earlier days of the exodus. And the child who flew out the day after the programme was able to be assessed immediately. The other four children had to wait up to three years before they**

received an appointment for their child's assessment. One parent received their appointment with mixed feelings:

**"I felt - not pressure - but as if it was something that I really should do. So I wrote to the Peto hoping really that I would never hear back from them. I wasn't too keen to go traipsing out there but when I did get the appointment to go I decided I would go just to see what it was all about. My husband said that it was a waste of time - a ten minute interview and you turn around and come home - what good is that going to do."**

**But this mother knew that her decision was the correct one immediately after the assessment:**

**"The assessment, I was really impressed with it. They were so positive that there was lots of potential there. It was the first time anyone was ever that positive. Before that I just got the impression that she would have surgery, and the wheelchair was her only option."**

**"We went for assessment at Easter and I remember thinking it was a pity we had to go all the way to Budapest. We had to stay over a Saturday night - I think to get it cheaper - all for one hour at the clinic."**

**"And the first trip out was just an assessment so we decided that we would make it our holiday, a week in Budapest... And the assessment was just very, very brief. They just took Martin in and asked him a few questions, then they asked him to lift his arms and to roll over, and their reaction when he rolled over, we just knew that they were going to accept him."**

**One mother described the importance of and the tension surrounding the brief assessment thus:**

**"At the time she was assessed the pressure on places was the greatest and so many children were being rejected. To be rejected would have been like the final blow, it would have been like hearing that there was no hope. The rumour in the Hotel was that the first children assessed every day had a better chance of being accepted. So we went to the Institute an hour before the assessments started and there were already three families there before us. The assessment was done by two Conductors and when they said they would accept her it was so fantastic."**

**After the children were accepted as suitable for Conductive Education, the families were given appointments to return for periods of one or two months which was all that Western families could expect at that time. However, the family who flew to Budapest the day after the documentary was offered a far longer stay than was later possible. The mother describes the lonely decision to take up this long-stay place:**

**"Going to Budapest in 1986/7 as we did was quite something - we were still going behind the Iron Curtain. We really didn't know what we were facing into and people kept warning me off it. 'You shouldn't go there', and 'Don't bring a camera with you', 'Be careful of this and that', and 'the Communists' and all the rest. But it wasn't as bad as all that. I stayed in a hotel for the first two nights, I think, and then the Institute asked me if I'd like to stay on for - I don't know how long they wanted me to stay on for at that stage. But I said I couldn't, so I stayed on for a week. We moved out of the hotel and into a little flat that we managed to find. We went back shortly after that and stayed for a month and that was terrible. Ben didn't settle at all. When we came home I said that I would never, ever go back**

there again. However, they asked us to go back and after a lot of soul-searching and encouragement from friends, family and colleagues at work, who more or less told me that I couldn't refuse to go, I decided very reluctantly and very sadly to go over there. And I knew that when I did go that I wasn't just for two or three months or six months, that I was going for a much longer time - I knew that in my heart and that's what made me very sad. But we went anyway. But we really spent almost three years at the Institute - two and a half of them straight."

Apart from this child who had a long-stay place, one family in the study has been to Budapest twice since assessment, two children have been four times, one five times and one child has been eight times since assessment. Some children accepted and settled easily into life at the Institute:

"And from the first time we felt it was exactly as we expected - very intense. - And also Martin's reactions - because he was so enthusiastic about it and so willing from the start, they did give him a lot of attention."

for other children it was more difficult:

"We went into the Mother and Toddler group and it was dreadful, it was terrible, the heat and she wouldn't cooperate at all, sat by the door with her arms folded and wouldn't put on their rotten clothes. Total lack of co-operation and here was me stuck here with Ann. Oh, it was dreadful. It was just terrible and those two weeks were awful."

and one child who was reasonably settled on her first visit found it much more difficult to adjust on the second visit:

**"And at the end of the two months the Group Leader said that she had never met a child who cried every day for two months."**

**The mothers too, varied in their ability to adjust to life in Budapest with loneliness, lack of respite and boredom posing the greatest hardships:**

**"The weekends were the worst, I could tolerate the weeks much better."**

**"It was very lonely."**

**"It was so lonely and the time just dragged. The weather in January and February was awful and so there was no way to amuse the children at the weekends."**

**The difficulties and problems faced by mothers alone with their handicapped children in Budapest is well documented in Come Wind, Come Weather [1988] by Janet Read. However, for the families in this study the greatest strain was caused by leaving other young children at home:**

**"We went back at the beginning of September. We left the day before her sister started National School so I couldn't be with her for her first day at school."**

**"The effect on the rest of the family was mainly on my other daughter who was next to Ann, who would have been around six at the time. She became very withdrawn and very quiet - a bashful child anyway. And my mother used to sleep in the house at the time with her beside her in the bed, and she said she would wake up in the middle of the night, sit up and say nothing but sit there."**

**"But it was hard leaving Andrew [son] and Michael [husband] behind and it didn't get any easier with every visit, it will never get any easier.... I find it very lonely out there and at home they find it very lonely."**

**"I feel the fact that having to leave the family was the biggest thing really. If I had no other children and no husband, you might as well be in Hungary and stay there and maybe get a job over there just to support yourself and your child. But in my position I had a husband and then I had two other children... They miss me and Maire [older daughter] got all sorts - she had to go and see the doctor while I was away the first time with pains in her stomach and James [younger son] went off to Montessori school and was actually thrown out. He was unhappy. He was all set to go and when I came home at Halloween I was just met with the news that he had been asked to leave. So it did affect him. And it is a big responsibility for Philip [husband] trying to work and look after the others - even though I had someone in for James. Leaving the family really was the biggest thing - there's never a right time to leave, there's always something, somebody starting school, somebody making their Communion. I have a teenager who needs me starting Secondary School. There was always something, there was never a right time to go."**

**Compared to the physical and emotional hardships involved in bringing their children to Budapest, the financial costs were not**

considered to be a very great obstacle. One of the six families financed the visits themselves:

**"The costs for me weren't great because I felt it was no more than a family holiday would cost."**

and the other five families fundraised and had money fundraised for them by friends, families, colleagues and their communities.

Parents then, made a decision to go to Budapest based, in five of the six cases, on a television documentary and in the fifth cases based on a newspaper article. To those unaware of or complacent about the level of care which the families had received up to this point, such a decision may seem whimsical or impetuous. Yet parents of physically handicapped children must be amongst those least likely to act on an impulse which would result in the division of their families and a commitment to spending periods of time in what was then an Eastern Block country. But the decision was in fact born out of a deep disillusionment with facilities and attitudes experienced at home and a desperate need to find a situation which offered the hope that the potential which they felt was within their child might be exploited. Given the hardships involved in transporting a physically handicapped child to Budapest and living there, for months at a time, while leaving the rest of the family at home, a decision based on whimsical grounds could not be expected to maintain the resolve necessary for families to return to Budapest again and again. Yet only one mother felt disillusioned with her experiences mainly due to

**organisational difficulties which existed within the group to which her daughter was assigned:**

**"I was a little disillusioned I must admit after Budapest because we went in full of all the work Sinead was going to do. Sinead was prepared to work hard, we brought her in and there were queues of children and we waited. I think we spent the whole first day waiting for her to be assessed into the group she was put in. We came in the next day and we were told 'I think she needs a sage bath' and to bring her in earlier every morning and I ended up giving her the sage bath myself. There wasn't anyone around to show me what to do or anything. So I gave her the sage bath and then I walked her into the room. But I noticed that some people used to walk them out again, this is what always used to amaze me. There was another little girl who used to have a sage bath and her mother used to walk her out to be walked in again. And that to me was crazy though it made sense in that she wasn't sitting down waiting for three-quarters of an hour. She was getting walked by a Conductor. I suppose I was a bit disillusioned, I thought there was an awful lot of wasting of time. Groups were huge and I just felt there was an awful lot of children in the group who were well able to do the work really well and there weren't enough to help the children who weren't able to do it. So I think there was quite a bit of aggro that time, complaints about needing Conductors. And then we got a Group Leader. And the Group opposite seemed to work much harder and work on time."**

**But even this mother considers her two visits to the Peto Institute to have been a valuable and worthwhile experience:**

**"It was definitely worthwhile to go, I'm glad I went. I learned a lot and we still do a lot of the work and we learned a lot. I am a firm believer in Conductive Education. I just feel it's a shame that you have to go**

**all the way out to Budapest. It's definitely benefited Sinead in her sitting and everything."**

**And the other mothers are uncompromising in their conviction that their visits to the Peto Institute were worthwhile:**

**"Really I have no regrets at all about taking Martin over there. He has learned to stand, which all along we felt was so important because he is a big boy and because he is going to be very heavy. He's going to have to be able to stand and even move a little bit. Also mentally, his concentration, it was the big thing they said at school from his going out, his concentration has improved so much. And his hand work is very good now and he can feed himself and he can dress his top half. For Martin it has helped him so much."**

**"It was very worthwhile and I'd do it all over again. Ben walks around the house on two sticks, he became much more independent than I thought he could become here. He benefited from being away from home and learning about other people and their language and their customs and to cope with all of that."**

**"Definitely I think it was worthwhile. I don't see that she would be as good as she is today without having gone. The benefit is that she is walking, and if I hadn't gone and if I had continued to go to the [clinic] once or twice a year and the little bit of physio I was getting here at the time, it would never have happened."**

**"I learnt a lot myself, I suppose that that is the chief benefit because I hadn't a clue when I went out there how to deal with him. Working in with him I learnt a lot about stretches and all that, and proper exercises. And he has come on an awful lot."**

**"Definitely it helped. It is down to day to day management of the child and being focused. It showed what was possible and it gave us hope."**

**The satisfaction of the parents with their decision to travel to Budapest for help was not shared by the professional at home who were dealing with the children:**

**"Professionals had absolutely no time for it whatsoever - it was a load of bullshit as far as they were concerned."**

**As noted earlier in this study three of the six children had already had their therapeutic services withdrawn from them due to conflicts between the parents and the professionals. And in response to parents becoming involved with Conductive Education in Hungary the professionals once again reacted in a manner which belied their professional status and resorted to coercive tactics using State services as a weapon:**

**"The physiotherapist there was resistant to the whole idea of a child going to Peto. It even went so far as she contacted the Health Board saying we should not be entitled to different aids that Martin should have been entitled to. We had to buy his electric wheelchair simply because she wrote to them saying that if we could afford to go to Budapest we can afford to buy his own chair."**

**And this therapist tried to influence the parents through emotional pressure on the disabled child:**

**"The physiotherapist had a disgraceful attitude to Martin. At one stage she was, really it was a form of blackmail what she was doing, she was taking him in for physiotherapy and in the middle of it having little discussions with Martin about what he was missing by going out there and how much better and how much more exciting it would be to stay at home, how much he would miss his friends and the expense he was putting his parents to and going out knowing it wasn't doing him any good. For Martin's sake, for a long, long time, I didn't say anything but I thought if only she would get on with the quarter of an hour's work she was supposed to do instead of brain-washing Martin in another direction. She never discussed it with me but what she was trying to do emotionally with the child was just disgraceful, it really was. On different days he would come home in different states because of the things she was saying to him. She never accepted that there was a physical improvement. What she was saying was it was a waste of time going over there. Particularly after coming back, he was on such a high that the school work and everything else, he had such a greater image of himself, everything improved, but in fact, what she was doing by taking him in and saying things like 'well, it's not doing you any good' and 'The expense you are putting your parents to.' and 'how you are missing all the fun while you are away'. Things like this and it was happening an awful lot. And then eventually I did have to stop it because he wasn't getting any therapy and what he was getting was really very bad. The physiotherapist, one way or another, never acknowledged that Martin had improved or disimproved."**

**The physiotherapists' refusal to discuss or even acknowledge the issues surrounding the parents' decision to take the child to Budapest provides another example of the lack of communication between parent and professional which was so prevalent in the early years at**

**any time of crisis. This lack of communication deprived the parents of a basis upon which they could develop hope. And it is this lack of hope, rather than Cummins' [1988] 'magical thinking' which Sutton [1990] believes drove so many parents to Budapest. Of parents who bring their children to Budapest he writes:**

**"Whatever their individual background, one hears strikingly similar stories of the services back home - that they offer no hope. The absence of hope is despair: I recognise that I am stating what to some is still unstatable, that consumers go the Peto Institute not just because they hope for beneficial experiences there but that they might also be actively DRIVEN to go there. In fact they would go any where, and some of them have, by what they perceive as the hopelessness of provision at home. There is an implied - and often explicit - value judgement here. People are going to Budapest because they hope to find something BETTER there and hope for CHANGE FOR THE BETTER back home." p.2.**

**If a parent finds this hope in Budapest it relieves them of anxiety and removes the stress that such anxiety causes:**

**"Well, for my husband and myself we found the greatest benefit we got out of Budapest was we weren't at all anxious about Martin anymore. We knew what to do with him to help him, and we found that at least we were doing the very best we could for him, and if it worked, it worked, and if it didn't then we were satisfied that we had done the very best for him. But we became much more relaxed with him. All along the only anxiety we had for Martin was that we knew he wasn't getting what he should have to help him improve and after the first time out we knew that this was it, at least he had improved and it was of benefit to him."**

**Lack of adequate provision, lack of communication and lack of satisfactory relationship with professionals created a lack of hope and a sense of despair in the parents in this study which drove them to Budapest. Yet any hope that things might change for the better back home did not materialise as parents who went to Budapest due to lack of provision were then punished for going by having what little service their child was receiving withdrawn from him as a punishment:**

**"I went to the [clinic] and begged them, before ever I went to Budapest, to take Ann for one week. Just to take her for one week, just to get her motivated and get something going and they said it was totally out of the question. And they wrote back to my husband and I and said we were almost trying to get rid of the child and it was our responsibility and get on with it. I have the letter to prove it and they can't say they didn't do it. Once I went to Budapest I went up again and they had a summer course going and I asked could Ann go and they said because I was going to Budapest I would not be considered. 'But' I said 'if you take me I won't go to Budapest' but they didn't take me. And she definitely needed all that kind of motivation at the time. As far as I was concerned nothing was being offered here, nothing. Had I got any semblance of a service I would never have gone and I wouldn't go back again if someone was offering me something, if the service was available here. You couldn't even buy the services here. The physiotherapists here - I rang up so many of them - it was too specialised a case. Yet I'm no physiotherapist and I'm expected to do it all. I'm not a physiotherapist. I don't know and I'm trying to muddle along. I'm prepared to pay them and they still wouldn't take her."**

**Summary Conclusion: Peto Institute.**

**The parents in this study travelled behind the Iron Curtain to live there for periods of time with their handicapped children, leaving other family members at home on the basis of a single television documentary or newspaper article. The decision could be made so instantly because it was a response to the years of perceived negativity and rejection which they experienced at home. In Budapest they found positivism and hope, and a level of therapeutic provision which they felt that their children required in order to maximise their potential. On returning home they once again encountered the same reactions from the professionals which served to drive them to Budapest in the first place.**

## **SUMMING UP OF INTERVIEW SECTION.**

**The evidence presented in the in-depth interviews establish the extent of the lack of support available to families with a disabled child and how this served to alienate and isolate the parents from the professionals with whom they were dealing. It further establishes how significant this lack of support and alienation was in determining the parents' choice to seek assistance at the Peto Institute in Budapest.**

**Parents experienced severe trauma at all the crisis points in their childs' development, through both lack of available support structures and because of the insensitivity with which they and their children were treated.**

**Diagnosis was often delayed and then insensitively given. No information or support was offered at the time of diagnosis to help parents to understand this diagnosis or its implications. In some cases, an additional, incorrect diagnosis of a mental handicap was given which served to increase the parents' distress and alienate them further from the professionals.**

**Therapy is important for both the disabled children and their families. For the child it is the means by which their physical potential might be maximised and secondary deformities prevented. For the parents, therapy should provide a close, supportive and learning relationship with a professional. Instead, in the cases presented in this interview section, therapy proved to be a source of frustration and anxiety to the parents. The children did not receive either the quantity or the quality of therapeutic provision which the**

parents felt that their children required. And once again, insensitivity to both the child and his/her parents all too often characterised the manner in which the professionals related to them.

The time at which the disabled child entered the education system was characterised, once again, by a lack of proper assessment, counselling, support or advice. The parents of those children who were attending 'special' schools were frustrated by the low expectations of the teachers for their children. The parents of those children who were in mainstream schooling were constantly having to struggle to try to compensate for the lack of support, or to battle for the provision of support for their child and his / her teachers.

The six families in this section of the study experienced and dealt with the arduous of travelling to and staying in Budapest in different, personal ways. However, some common threads ran through all their experiences. The families who had not already been expelled from the Irish system by the professionals, experienced disapproval from some, if not all of the professionals with whom they were dealing - up to and including service withdrawal.

None of the families regretted their decision to turn to Conductive Education despite the difficulties which this decision created. However, one family had more reservations than the others - mainly caused by internal difficulties within the Institute at this time.

**In Budapest parents experienced their children receiving a method of therapy delivered with an intensity which they felt their children required. For the first time they saw their children being treated with positivism and hope, and some achieved an understanding of their child and his / her condition which they hitherto did not have.**

**Parents perceived the provision available at home as being lacking in support and optimism and deficient in its capacity to ameliorate or remediate their child's condition. Neither was the home provision able to assist the families at the crisis points in this unasked for and unaccustomed experience. By contrast, the Peto Institute seemed to offer much of what was perceived to be missing at home. It could be suggested that it was the deficiencies in the provision available at home which drove these families to the Peto Institute in Budapest. And , on returning home, the children and their families were treated with the same negativity and lack of support which sent them to Budapest in the first place.**

### **CHAPTER THREE: SURVEY.**

**It could be said that certain conclusions can be validly arrived at from the fore-going data. The overall picture emerging is that parents suffer often extreme difficulty at different points in the development of their disabled child.**

**It could furthermore be argued that those difficulties arose because of professional inadequacies on the part of those concerned with the care of the children: paediatricians, nurses, physiotherapists, teachers. All seem to have shown serious inadequacies when confronted with the difficulties of parents who found themselves in the unexpected situation of caring for a child with a disability.**

**However, it could furthermore be surmised that the parents interviewed were not typical of other parents in their situation and may have created difficulties for themselves and the professionals dealing with them. In order to test further the hypothesis being explored - namely that parents turned to Conductive Education because of the inadequacies which they perceived in the standard or statutory provision - it is necessary to sample a wider section of parents who turned to Conductive Education.**

**Accordingly a survey was designed and circulated to eighty-seven parents who became involved with Conductive Education. The mailing list was compiled with the help of groups involved in promoting, fundraising for, and supporting families involved in Conductive Education. There were forty-six valid responses to the survey giving a response rate of 54% and this was considered by the**

researcher to be a very satisfactory return. While parents of children with disabilities are amongst those parents with the least amount of time to dedicate to form filling they are also those who are requested to do so with most regularity.

Given the circumstances of the survey and the restraints under which the research was conducted it was not possible to effect an adequate pre-test. There were constraints of time which would have delayed the process overlong; there was a lack of professional access to technologies - computers etc. and perhaps most importantly of all the researcher was aware of the pressures and stresses which constrain parents of children with disabilities. Furthermore, given the size of the sample and given the population, it would have been extremely difficult to gather a control group to test adequately the survey. Given these and other constraints a one shot survey was decided upon.

The following were the objectives of the survey:

A. To establish base-line data on the parents, families and children to see if there were constraints which might be significant in the critical choices which they made.

B. To establish whether a larger proportion of parents had experienced difficulties with professionals at the time of the diagnosis of their child's disability.

C. To discover whether a larger proportion of parents who turned to Conductive Education experienced difficulties with the quality and frequency of provision by statutory or other agency.

**D. To discover to what extent the larger proportion who turned to Conductive Education were motivated by negative feelings about this provision when turning to Conductive Education, experiencing the hardships and difficulties of long travel and long periods away from home and whether the forms of Conductive Education which their children underwent were different to those forms of therapy experienced at home and whether they were judged to be better, more professional and generally more helpful and effective for the children.**

**The survey also intended to ascertain to what extent parents who turned to Conductive Education experienced rejection by home-based professionals.**

**A complete version of the questionnaire is available in the Appendix.**

**Section D of the survey is the most central to the discussion of Conductive Education. It is therefore "weighted" accordingly and comprises the largest section of the questionnaire.**

## **SECTION A**

The purpose of Section A was to establish base-line information concerning the respondents and their families. The responses yielded profiles of parents, the child\children with disabilities and his/her siblings.

### **Q.A.1. Relationship of respondent to the disabled child.**

This question sought to establish the respondent's relationship with the disabled child who received Conductive Education. By implication it also identifies the role of primary care-giver.

All 46 respondents answered this question.

<b>RESPONDANTS RELATIONSHIP WITH DISABLED CHILD</b>			
<b>Mother</b>	<b>Father</b>	<b>Joint</b>	<b>Total</b>
<b>40</b>	<b>4</b>	<b>2</b>	<b>46</b>

Overwhelmingly the mother was the respondent. 40 mothers answered the survey, 4 fathers answered, and in two cases both parents answered jointly. Mothers, therefore, were the respondents or the co-respondents in 91% of cases. This would reflect the common family situation of the mother as the primary care-giver.

In the case of a family with a disabled child, studies have shown that mothers carry the major burden of caring for the child with a

handicap. [Cooke, Lawton. 1984], [Wilkins 1979]. Thus to the mother, in the vast majority of cases, would fall the obligation to deal with the medical professionals - who are predominantly male. This primary care-giver would also be most closely involved with therapeutic provision, and be best placed to be aware of any deficiencies therein. This is also the parent who would be most likely to research and seek out alternative therapies.

**Q.A.2. Marital status of the respondent[s].**

This question sought to establish the marital status of the respondents, and, by implication, to set out the kind of family ethos most supportive of a rigorous pursuit of alternative therapies for a disabled child - such as Conductive Education.

All 46 respondents answered this question.

RESPONDENTS MARITAL STATUS					
Married	Single	Separated	Widowed	Other	Total
39	2	1	2	2	46

The overwhelming majority of the respondents were married [83%]. 39 respondents were married, 2 were single, 2 were widowed, 1 was separated, and 2 indicated 'other', but did not specify.

**This would suggest that the respondents to this survey largely belonged in a stable marriage relationship and might further suggest that such stability is a prerequisite to being able to withstand the rigours and privations experienced by families as a result of becoming involved with Conductive Education. Such involvement necessitated long absences from home, from husband and from other children, a long journey with a disabled child and weeks and months spent living in a foreign country. It would clearly be more easily endured from the basis of a stable home-life. However, it also the case that it was the absence of what would generally be considered a stable family life that made it possible for a single mother who answered the survey to spend two and a half years in Budapest at the Peto Institute.**

### **Q.A.3. Parent's Age.**

**This question sought to establish the age range of the parent respondents, and to imply the degree of physical and mental maturity necessary in undertaking a Conductive Education approach to therapy for a disabled child with the added complications of travel to a foreign, Eastern-Block country.**

**All 46 respondents answered this question. One respondent answered for both herself and her husband which gave a total of 47 responses.**

AGE OF RESPONDENTS					
28 to 39 years	40 to 47 years	48 to 56 years	No answer	Other	Total
24	13	8	1	1	47

There is a large cluster in the early middle age range and a total lack of any respondents under 28 years of age. This would suggest that a certain level of parental maturity was necessary in order to embark on Conductive Education and also that the privations involved were too great for many parents of a more advanced age. In their case also, there would probably be less likelihood of success, the children presumably being older. The responses may also suggest that the families in these age ranges, rather than younger ones, have achieved a level of family and financial security which permits them to make a decision such as embarking on alternative therapies.

#### Q.A.4. Parent's occupation.

This question sought to establish any relationship between position within the class structure and a willingness to turn to Conductive Education.

41 respondents answered this question as pertaining to the father's occupation. 5 respondents were lone parents through never having married, separation or widowhood. The father occupation was not given in these cases thereby giving 41 responses to this question.

FATHERS OCCUPATION - CLASS PROFILED				
A Higher Professional / Managerial	B Lower Professional / Managerial	C Other non-managerial but professional	D Skilled manual	E Semi- skilled manual
6	5	8	17	2
F unskilled manual	G Home Maker	H Unemployed	Total	
0	0	3	41	

**46 respondents answered this question as pertaining to the mothers occupation.**

MOTHERS OCCUPATION - CLASS PROFILED				
A Higher Professional / Managerial	B Lower Professional / Managerial	C Other non-managerial but professional	D Skilled manual	E Semi- skilled manual
0	1	9	7	0
F unskilled manual	G Home Maker	H Unemployed	Total	
0	30	0	46	

**If a family's position is to be determined on the basis of the father's occupation, then a large majority of respondents were in a middle or upper middle class bracket.**

**It may be that it was only families from these class brackets who took the time and made the effort to fill in and return the survey. The survey had a return rate of 54%. Alternatively, if the respondents**

are typical of all the families who experienced Conductive Education, it would appear that the phenomenon was mainly a middle or upper middle class one. Given that turning to Conductive Education often involved ignoring or opposing the medical and therapeutic professionals and required a certain level of education and personal and financial security, this is an unsurprising result. As many families had funds raised for them by friends and community groups, it may also be that these classes of people were better placed to generate such support.

**Q.A.5. Parent's level of education.**

The purpose of this question was to establish the level of educational attainment of the parents of those children who experienced Conductive Education, because of its implications concerning informed decision making.

41 respondents answered this question pertaining to the father's level of education. The five families which consisted of only one parent did not respond.

FATHER'S LEVEL OF EDUCATION				
National school	Second level	Third level	No answer	Total
1	26	14	5	46

**45 respondents answered this question as to the mother's level of education. While it is not clear why 1 respondent did not answer it might be suggested that someone with a low level of education might feel embarrassed to answer such a question.**

<b>MOTHER'S LEVEL OF EDUCATION</b>			
<b>National school</b>	<b>Second level</b>	<b>Third level</b>	<b>Total</b>
<b>3</b>	<b>28</b>	<b>14</b>	<b>45</b>

**29 of the 30 'housewives' noted their education levels. A possible reason for the other respondent not answering was suggested in the last chart.**

<b>HOUSEWIVES' EDUCATION LEVELS</b>			
<b>National school</b>	<b>Second level</b>	<b>Third level</b>	<b>Total</b>
<b>3</b>	<b>17</b>	<b>9</b>	<b>29</b>

**All four fathers who were noted as unemployed had completed Secondary school. One had been a business man, one a carpenter/joiner, one a mechanical worker and one did not specify previous employment.**

**All but one of the fathers and two of the mothers were educated to at least second level.**

**A significant proportion of parents had a third level qualification - 14 [30%] of the fathers and 14 [40%] of the mothers.**

**'Housewives' are those women who classified themselves thus, having no paid employment outside the home. Examination of the educational attainment of the 'housewives' establishes that 9 [30%] of them had a third level qualification. Another 4 [13%] of the mothers are qualified nurses. This large number of highly qualified mothers who are working full-time in the home would suggest a well educated and probably highly competent body of women well placed to take on the arduous involved in turning to Conductive Education.**

**As with question A.4., it may be that the more educated parents found the time and made the effort to return the questionnaire. However, if the respondents are typical of the families who sought Conductive Education, they would appear to be a reasonably well educated group.**

#### **Q.A.6 Number of children in family.**

**This question and the following question sought to place the disabled child in the context of the number of his/her siblings, and to establish a profile of a family most appropriate to sustaining the rigours involved in turning to Conductive Education.**

**All 46 respondents answered this question. As there are two sets of twins involved in the survey, the total number of responses to this question was 48.**

TOTAL NUMBER OF CHILDREN IN FAMILY						
Only child	2 children	3 children	4 children	5 children	6 children	Total
5	10	19	12	1	1	48

**34 [69%] of the 48 children come from families of 3 or less children and only 2 from families of greater than 4 children. This would support the suggestion that smaller families better might facilitate long periods of absence from home for a parent and a child.**

**Q.A.7. Ages of children-with a disability.**

**This question sought to establish the ages of the children with a disability in an attempt to develop a profile of the children who went to Budapest.**

**All 46 respondents answered this question. The involvement of two sets of twins brings the total number of responses to this question to 48.**

AGES OF DISABLED CHILDREN				
0 - 6 years	7 - 12 years	13 - 18 years	19 - 24 years	Total
8	27	11	2	48

**There are 3 sets of twins involved in this survey. In 2 of these families both twins have Cerebral Palsy and in one set only 1 twin is affected. One set of twins are second and third in a family of 4. One set of**

twins are the eldest of 4. The twins of which only one child is affected are fourth and fifth of a family of 6 children.

The children involved in the survey range in age from 5 to 21, with a strong peak 27 [ 56%] in the 7-12 year age grouping.

There was a total absence of children under five years of age and several reasons can be suggested for this. It could be that the 'road' to Budapest is now somewhat easier since the fall of the Iron Curtain and therefore the younger families who are now going out are much more self-contained and are not becoming part of various ad hoc 'Peto Parent's' groupings from which it was possible to draw up a mailing list for this survey. It might also be that Conductive Education is now available to some extent in this country through Summer Camps and pilot projects. These might be preferable to parents of younger children as these children would be placed in 'Mother and Toddler' groups in the Peto Institute and these groups work for only two hours a day. The arduous involved in going to, and staying in Budapest for just two hours a day are harder to justify than when a child is older and 'working' for six or seven hours a day.

There was also only a scant 2 [4%] representation of the over eighteen age group. In the years of peak demand for places in the Peto Institute preference was given to the pre-teens, as they believed that the younger children had greater potential for improvement. Therefore the older children were much less likely to be accepted.

It is also the case that parents of older children are less likely to interrupt their child's education. Disabled children are at a

**disadvantage in the education system because the State system makes few allowances for the handicaps which their disabilities impose upon them. Few disabled children will have the option of manual work open to them and therefore education is more important to them than to their more able-bodied peers if they are to succeed in the open workforce.**

**Therapy, then, is generally the priority for parents up to the age of seven or eight and then formal schooling tends to assume higher importance. The Peto Institute in Budapest provides the Hungarian children with both an academic and physical education and the children follow the National curricula. Conductors are qualified to teach at primary school level. The daily programme followed by the Western children was a purely physical one - this was because most of the children were only there for a month or two at a time, because the age range of the children in any one group could span up to eight years, because there would be children from several countries in any group and there would therefore not be a common native language for them to be taught through, and because they would all be following different curriculums in their home countries. In this respect, Conductive Education, as experienced by most Western children, even in the Peto Institute, differed from that available to Hungarian children.**

**The children are almost evenly divided between the sexes - 23 males and 25 females.**

**The position of the disabled child/children within the family is well spread out with 11 being the eldest, 16 being the youngest, 11 being placed elsewhere in the family and 5 being only children.**

#### **Summary of Section A.**

**The responses to Section A of the survey presents the portrait of the 'typical family' of respondents as being predominantly middle-class, well educated and small to medium in size. Considering that families who turned to Conductive Education had to make the psychological break with the 'orthodox' therapies and organise the mental, physical and financial resources to travel and to stay away from home, often for long periods of time, it is unsurprising that this should appear as the appropriate profile.**

**A picture also emerges of a strong, well educated mother, whether this mother is combining a job or career with caring for a family that includes a disabled child, or working solely as a home-maker and primary care-giver. Such a mother is likely to be resourceful and sensitive to, but not overpowered by, hostility and indifference and therefore very persistent in pursuit of the child's best interest as they would perceive it to be.**

**The picture of the child that emerges is one that is most likely to be between 7-12 years of age, and from a small to medium sized family.**

## Section B.

The purpose of Section B. was to explore the experiences of parents at and around the time that their child's disability was diagnosed. It looked at pre-diagnosis experiences; diagnosis; post diagnosis provision of therapy; and availability of information and support structures at this time of crisis.

Diagnosis is thus seen as a defining moment, determining parental attitudes of satisfaction or dissatisfaction with local provision and which might thus substantively affect a decision to turn to Conductive Education abroad or at home.

### Q.B.1. Age at which Child's Disability was Diagnosed.

This question sought to establish the age at which the children were diagnosed as having a disability.

All 46 respondents answered this question. The involvement of two sets of twins bring the total responses to this question to 48.

AGE OF DIAGNOSIS - 3 MONTHLY INTERVALS						
Months	0 - 3	4 - 6	7 - 9	10 - 12	13 - 15	16 - 18
Number	9	6	1	10	7	6
Months	19 - 21	21 - 24	25 - 27	27 +	Total	
Number	1	4	0	4	48	

**Spina Bifida is a congenital defect which leaves a portion of the spinal cord exposed. Thus this condition is immediately apparent at the time of birth, or even before birth through ultra-sound scanning. Four of the children involved in this survey have Spina Bifida and were all therefore diagnosed at or before birth.**

**3 children were diagnosed as having Cerebral Palsy at the time of their birth. 1 respondent stated that this followed "problems with child's birth" and another that "hospital expecting this." These children would have had a particularly traumatic birth during which they would have suffered some lack of oxygen which caused damage to their brains.**

**26 [54%] of the children had been diagnosed as having a disability by the time they were one year old.**

**Excluding those children who were diagnosed at birth 23 [48%] of the others were diagnosed at between 10-18 months, while 8 [18%] were not diagnosed until they were 2 years or older.**

**Cerebral Palsy can often be difficult to diagnose, as many of the signs which would alert a Doctor to such a diagnosis -such as developmental delay, stiffness or floppiness - could also be attributed to other causes. Also these signs become apparent at different stages in a child's development. It is therefore impossible and incorrect to state that there is any particular age by which a child should be diagnosed as having Cerebral Palsy.**

**What is well established, however, and discussed in some detail in the interview section of this thesis, is that parental concerns need to be taken seriously as soon as they are expressed and that the**

professionals must then impart the diagnosis as soon as they have made it.

Indeed, some believe that parents should be informed as soon as a physician has even a suspicion that the child might have a disability [Bicknell, 1983], [Fox, 1974]. If this does not happen then the trauma of the diagnosis can be greatly exacerbated. An informative addition to this questionnaire would have been a question to establish any delay which existed between first suspicions and satisfactory diagnosis, as, it can be seen from the interview section, any such delay causes extreme trauma to the parents. Prompt diagnosis is also crucial in that it enables the therapeutic professionals to become involved at the earliest opportunity.

**Q.B.2. Who first suspected that the child might have a problem?**

This question sought to establish who, most often or consistently, raised the first suspicions that the child might not be developing as would be expected, and to reflect on the significance of this finding for parents and professionals.

All 46 respondents answered this question.

FIRST SUSPICIONS OF DISABILITY						
At birth	Parents	Other relatives	Develop-mental clinic	G. P.	District Nurse	Total
7	23	1	9	4	2	46

**The problem was immediately detectable at birth in the cases of the four children with Spina Bifida. In the cases of three of the other children with Cerebral Palsy the birth process was sufficiently traumatic to make a diagnosis of Cerebral Palsy possible at that time.**

**Apart from the seven children who were diagnosed at the time of birth, in more than half the other cases 23 [59%] it was one or both of the parents who first detected a problem, which is consistent with the findings of other studies.**

**In the earliest stages of their lives, for different reasons, babies are seen by health professionals - District Nurses, G.P.s for inoculations etc. and doctors at Developmental Clinics - and it is therefore surprising that a greater percentage of children did not have their difficulties detected by any of these. For most parents the possibility that their baby might not be 'normal' is an unthinkable idea to be pushed aside until the facts can no longer be ignored. Therefore one might reasonably expect that in most cases parents would be the last to suspect that their children had a difficulty. In the case where they do, the burden of this suspicion can be a traumatic one for the parents, which can only be relieved by a prompt and sympathetic diagnosis where one is justified.**

**Q.B.3. Difficulty in Obtaining Diagnosis.**

**This question sought to establish how many parents experienced difficulty in obtaining a diagnosis, as any such difficulty can make the trauma of diagnosis both more extensive and more intense.**

**All 46 respondents answered this question. The respondent who answered 'Not Applicable' probably did so because her child's disability-Spina Bifida- was apparent and therefore diagnosable at or before birth.**

DIFFICULTY IN OBTAINING DIAGNOSIS			
Yes	No	N / A	Total
19	26	1	46

**Given that 7 of the families received a diagnosis at the time of birth in exceptional circumstances and hence may be discounted from consideration among the 'No' answers, then only 19 [41%] obtained a diagnosis without any difficulty. This is significant because of the increased trauma that families which had difficulty in obtaining a diagnosis would have suffered at a time that is already stressful. Studies, such as those of D'Arcy [1968] and Drillien [1964] also suggest that parents who are told early are better able to adjust than those for whom the diagnosis or disclosure is delayed.**

**One respondent who answered 'Yes' elaborated:**

**"told child was slow, delayed and refusal to name tag, given a genetic disorder first [Neurofibromatosis] then 6 months later Cerebral Palsy., then later severe mental handicap."**

**One respondent who answered 'No' qualified her answer thus:**

**"No but clinical language is hard to understand"**

**Q.B.4. Parents' Perception of Professionals' Difficulty in Diagnosing.**

**This question sought to establish to what, if at all, parents ascribe the professional's difficulty in diagnosing their child's condition. This is significant because of the implications it will have for the parent/professional relationship.**

**20 respondents answered this question. 3 ascribed the difficulty to more than one factor producing a total of 26 responses to this question.**

<b>ARENTS PERCEPTION OF REASONS FOR PROFESSIONALS DIFFICULTY IN DIAGNOS</b>					
<b>Incompetence</b>	<b>Concern for parents</b>	<b>Lack of certainty</b>	<b>Ignorance</b>	<b>Professional's pride</b>	<b>Total</b>
<b>12</b>	<b>1</b>	<b>4</b>	<b>7</b>	<b>2</b>	<b>26</b>

**19 families who answered the previous question replied that they had experienced difficulty in obtaining a diagnosis yet 20 respondents**

answered this question. This indicates that 1 parent who did not register a difficulty with diagnosis recognised that professionals showed some sort of problem with diagnosing.

12 46% of responses attributed the professional difficulty to incompetence which indicates a serious undermining of the parents faith in the professionals' abilities at a very early stage.

The time around the period of diagnosis is a critical one for parents and its importance is discussed in detail in the interview section of this thesis. This period can lay the foundations of the relationship between the families and the professionals who are to play a huge role in their lives in the future. It is vital that mutual trust and confidence be established at this stage, if this relationship is to be a successful one. One parent considers the professionals to be less competent than an experienced parent:

**"when the children were diagnosed many people said they knew there was something wrong. If one had older children, parents and anyone dealing with young babies would or should have known it was not right."**

Another respondent likewise was unable to develop a belief in the professionals as allies:

**"You are only told what you are capable of asking for. If you don't know the question to ask you are considered happy and brushed off."**

**It is disturbing that a good proportion of respondents to this question should have experienced difficulties with the professionals at this early and critical stage.**

**Q.B.5. The Possibility of Wrong Diagnosis.**

**This question sought to establish how many families were told that their child had a mental handicap that they did not in fact have, as such a wrong diagnosis is both very traumatic to parents and also further undermines the parents faith in the professionals on whom they have to rely.**

**45 respondents answered this question. It is not clear why 1 respondent did not. Of the 2 respondents charted as 'other', 1 was a parent of a child with Spina Bifida who stated that the question was 'not applicable' but who did not elaborate. The other respondent was, at the time of diagnosis, a foster mother to the child who she later adopted. She stated that she would not have been privy to any diagnosis at this early stage.**

POSSIBILITY OF WRONG DIAGNOSIS			
Yes	No	other	Total
14	29	2	45

**Given the trauma which it may cause, an unacceptably high proportion - 17 of the 41 [41%] respondents, received an additional diagnosis of mental handicap or the possibility of a mental handicap with which they did not agree. It is evident from informal comment to this question that this wrong diagnosis is one which often upsets the parents greatly both because it does not match the parents' own experience of the child's ability and also because of the implications they foresee it will have in terms of the child's future education at school:**

**"When she was the age for school the Doctors wanted to put her in a mental handicap school. I had to fight very hard to get her a helper at the school she now attends."**

**"We were told she was mentally slow at two years. Now she is in 2nd class normal school and in the top hole."**

**Further trauma can be caused if a diagnosis is not only erroneous but also given in a clumsy or thoughtless way. One family had their twin sons diagnosed as having Cerebral Palsy by a specialist clinic without any mention of the possibility of a mental handicap. When the following day a nurse from the Health Board arrived to discuss mental handicap they could not be sure whether the diagnosis had been made or not:**

**"When children were first diagnosed of their handicap by the [clinic] there was no mention of a mental handicap but one day later a nurse called from the Health Board to tell us about mental handicap - which at this stage was not assessed by the clinic."**

**It can therefore become a cause of conflict between parents and professionals which can lead to a weakening of trust within this relationship. One respondent believes that there was an ulterior motive behind the diagnosis:**

**"I am not convinced that a child can be diagnosed as severely mentally handicapped at two and a half years of age giving the service provider the means to get the child off their books and pass him on to another service provider. I do not consider the child as severe Mentally Handicapped at all."**

**That parents have to suffer their children being wrongly diagnosed as having a mental handicap causes one to question the extent of the knowledge of some of the medical profession on the subject of disability. Among the general public there is a general assumption that a physical handicap always has an attendant mental handicap. Sadly some doctors seem to make the same erroneous assumption.**

**Parents have, in fact, proven to be very good assessors of their child's developmental performance [Coplan 1982] and if doctors were to accept parents as partners in the assessment procedure much trauma and disagreement might be avoided.**

### **Q.B.6. Second Opinion or Referral.**

**This question sought to establish how many of the families surveyed sought or were referred to another agency or specialist. Expertise in the area of disability in Ireland has traditionally resided in two centres, in Dublin and one in Cork, for children with a physical handicap. Services for mentally handicapped children and adults are much more widespread. The centralisation of expertise has necessitated parents from outside the two main cities having to travel, often long distances, to avail of adequate services or to obtain a second opinion e.g. concerning a suspected wrong diagnosis by a local paediatrician.**

**All 46 respondents answered this question. One parent of a child with Spina Bifida felt that this question was not applicable but did not elaborate. As 2 respondents indicated more than one response, this produced 47 responses.**

<b>SECOND OPINION OR REFERRAL</b>			
<b>No</b>	<b>Specialist Clinic</b>	<b>Mental handicap Services</b>	<b>Children's hospital</b>
<b>12</b>	<b>26</b>	<b>4</b>	<b>2</b>
<b>Other doctor</b>	<b>N / A</b>	<b>Total</b>	
<b>3</b>	<b>1</b>	<b>48</b>	

**In common with some of the families in the interview section, one respondent to this question had her concerns vindicated immediately on consulting a different doctor. This, of course, raised the question**

**as to why the first doctor was unwilling or unable to recognise the existence of a problem:**

**"I changed my family doctor. The 'new' doctor saw there was a problem the minute I entered his surgery."**

**One family went to a service for the mentally handicapped to get an assessment of the child's intelligence:**

**"Yes, got opinion from Brothers of Charity who assessed the child as normal intelligence."**

**The Central Remedial Clinic is the national centre for diagnosing, assessing and treating children with Cerebral Palsy. It is therefore not surprising that 26 78% children who had been referred anywhere were referred to the Central Remedial Clinic.**

**While no other service provider or any individual has been identified by name in this thesis, it was considered to be appropriate to make the Central Remedial Clinic an exception to this because of its importance as the major service provider to children with disabilities in Ireland.**

**It would obviously be desirable that families would receive a diagnosis and a service close to their homes in order to minimise the expense and hardships involved in travelling with young children. In order for this to happen a greater number of the medical profession would have to become more aware of the nature of physical handicaps, of the**

need for early diagnosis. And professional resources necessary to make the diagnosis would have to be more widely available.

**Q.B.7. Parents Reaction to Diagnosis of Disability.**

This question sought to establish the emotional reaction of the parents to the information that their child had a disabling condition and to establish the intensity of any trauma.

All 46 respondents answered this question.

REACTION TO DIAGNOSIS OF DISABILITY				
Relief	Normal	Surprise	Distress	Shock
5	4	0	6	12
Disbelief	Trauma	Other	Total	
6	13	0	46	

The responses to this question show just how powerful and emotional a shock is the diagnosis of a disability in a child. 4 respondents characterised their reactions as normal although two of these elaborated that this was because they assumed that the condition was curable, and one because they did not know what Cerebral Palsy was. 6 respondents characterised their reaction as one of relief. In two cases this was because the child's problem at last had a 'name' and in one case because it was not terminal. Almost all respondents indicated

**that the time was one of great emotional difficulty and one respondent stated:**

**"We will never get over the emotional distress it has and will cause us."**

**Other respondents used phrases such as: "terror", "pain", "great sadness, "angry and afraid."**

**This reflects the findings of the English Spastics Society Report, 'Right From The Start', [Leonard 1994] The Spastics Society states that this report was one that 'demanded' to be written; their researchers had noted that whatever the subject parents of children with a disability were talking about, they repeatedly and spontaneously reverted to talking about the time of diagnosis. The Report notes how:**

**"again and again parents spoke of that time, remembering every detail and exactly how distressing and difficult it had been, in many cases painfully re-living it as they talked."**

**The report notes how much damage a clumsy or insensitive diagnosis can do and this certainly is a major contributory factor in ensuring that the time of diagnosis is a traumatic one.**

**But other issues are also involved: society as a whole does not know about disability nor does it value the disabled. In answering this**

question six respondents made the point that even though they had a diagnosis they had no idea what the label meant.

For parents the diagnosis is a leap into a negative unknown, but their trauma could be lessened by professional sensitivity at this stage. Parents need to know the facts and to be prepared for their future role, and also given some reassurance and support.

**Q.B.8. Previous knowledge about the disability.**

This question sought to establish the level of knowledge amongst parents about the particular disability before their child was diagnosed.

All 46 respondents answered this question.

PREVIOUS KNOWLEDGE OF DISABILITY			
Yes	No	Little / Very little	Total
0	38	8	46

Only 8 17% of respondents had any knowledge whatsoever about the disabling condition before their child was diagnosed, and this would reflect an ignorance in the general population to issues of disability. This general ignorance would make the diagnosis of a disability more intensely traumatic for parents. It would also indicate that

professionals have an important responsibility to inform the public, but especially parents of children with disabilities.

**Q.B.9. Information offered after diagnosis.**

This question sought to establish if the parents were offered any information about their child's condition after it had been diagnosed. Such information would be particularly important, as it has been established in the previous question, that few parents had any such knowledge prior to diagnosis.

43 respondents answered this question and it is not clear why the others did not do so.

INFORMATION OFFERED AFTER DIAGNOSIS		
Yes	No	Total
15	28	43

15 35% respondents answered 'Yes' to this question. However, 4 27% of these qualified their answer:

"A little"

"Very little"

"not extensive enough"

**"handed booklets, very little personal guidance"**

**28 65% of respondents answered 'No'. Given the deficit of knowledge about Cerebral Palsy and Spina Bifida in the population in general, the need for information at the time of diagnosis would seem to be crucial. According to the responses to this question this information is not forthcoming in most cases. Information can serve to reduce trauma. Whereas lack of information can lead to a sense of lack of service back-up and help, thus increasing the parents isolation and fears and thereby increasing the trauma.**

**Q.B.10 Parents' Sources of Information about Cerebral Palsy/Spina Bifida.**

**This question sought to establish from whence the parents got the necessary information to try to understand the diagnosis and thereby relive some of their trauma.**

**All 46 respondents answered this question which produced 63 responses as some parents indicated more than one response.**

<b>SOURCES OF INFORMATION ABOUT THE DISABLING CONDITION</b>					
<b>Personal reading</b>	<b>Friends</b>	<b>Other parents</b>	<b>Professionals</b>	<b>Voluntary organisations</b>	<b>Total</b>
<b>36</b>	<b>5</b>	<b>5</b>	<b>15</b>	<b>2</b>	<b>63</b>

**The great majority of respondents 36 78% relied on personal reading, either solely or in part, to obtain information on their child's disabling condition, which means that such information is available only to those with the education and resources to access it. Those without such resources are therefore denied the relief of trauma that an understanding their child's diagnosis and prognosis could bring.**

**Many studies, including the Warnock Report [1978], have emphasised the importance of the role of the parents in educating and maximising the potential of the child with a disability. The fact that parents can be left without information has worrying implications for the well-being of the child and for the quality of professional provision for the disabled.**

**Cerebral Palsy Ireland and the Spina Bifida Association are Voluntary Organisations whose functions are, in part, that of offering support and information to families, yet only 2 4% respondents received their information from these sources. It is hard to comprehend the professionals' failure to advise the parents of these sources of information and support, particularly when they themselves appear unwilling or unable to help the parents in this regard.**

**Only 15 of the 46 families 32% received information from professionals. As all the children were ultimately diagnosed by a professional this means that at least two thirds of them were handed a diagnosis without any explanation or information at all. Yet the need for early and continuing information has been stressed by many**

writers including Tarron [1980]. It is therefore unsurprising that many parents come to doubt the level of knowledge of and concern about their children and their condition amongst the professionals. This, in turn, makes it unsurprising that in years to come parents are receptive to alternatives such as Conductive Education which may be perceived as offering a level of positive care and support unavailable within our health system.

**Q.B.11 Parents Access to Support Groups.**

This question sought to establish whether the parents were informed of agencies which might offer them the information and support which might relieve some of the intensity of their trauma.

All 46 respondents answered this question.

PARENTS ACCESS TO SUPPORT GROUPS		
Yes	No	Total
6	40	46

One of the respondents who answered 'Yes' qualified it with 'but not immediately.'

40 87% of respondents were not informed of support groups. Information and support could serve to ameliorate some of the trauma

caused by the diagnosis. Yet the vast majority of respondents was deprived of this potential source of help at a time when they were particularly vulnerable.

Parents were further asked if they would have desired the information and support which a support group would give.

40 respondents answered this question. The question was not relevant to the 6 respondents who answered 'Yes' to the previous question and therefore had access to such groups.

PARENTS' DESIRE FOR SUPPORT GROUP INFORMATION		
Yes	No	Total
36	4	40

Some parents were emphatic about their need for such a group:

"very, very much so."

"very much so."

One respondent would have liked to have been given the option to make contact with a support group if and when they wished to. Given that parents need information and support at the time of diagnosis and that professionals appear to be unable or unwilling to supply this, the role of support groups could be very significant. Yet the majority 40 87% families did not receive any information about such groups

although the overwhelming majority of these 36 90% would have welcomed such information.

As with all of life's most traumatic events different people cope in different ways and at different speeds. Thus it is not too surprising that 4 respondents stated that they would not have welcomed information about support groups at this stage. What is important however is that such information would be available to them should they ever reach the stage that they felt that they could benefit from it. For parents not to receive such information at the time when they need it only increases their sense of isolation.

**Q.B.12. Parents' Perceived Need for Professional Support at the Time of Diagnosis.**

This question sought to establish if the parents felt a need at this point in time for professional support to alleviate the intensity of their trauma. It has been shown that even where a doctor can do nothing else but listen, that this listening alone is of great importance to parents [Hewitt 1970].

All 46 respondents answered this question.

PARENTS' NEED FOR PROFESSIONAL SUPPORT		
Yes	No	Total
36	10	46

**The large majority 36 78% of families who responded to this survey felt a need for professional support at this stage. Even at this early stage 2 4% respondents were disillusioned with professionals:**

**"rather support from other parents to understand our position. We had enough of the 'professionals' at this stage"**

**"not professional. Another parent who had gone through the same trauma would have helped."**

**and another felt that they needed information rather than support from the professionals.**

**The need for professional support is by now well established - Redman-Bentley [1982] emphasises how important to parents is a caring attitude on the part of professionals even where they can do no more than listen.**

**Q.B.13. Parents' Perception of Support Received at the Time of Diagnosis.**

**This question sought to establish the extent to which professional support was available to parents at the time of diagnosis. Support differs from information, which was the focus of the previous question, and would include consultancy and other services to offer advice and minimize the sense of trauma and isolation of parents.**

**All 46 respondents answered this question.**

PARENTS PERCEPTION OF SUPPORT RECEIVED		
Yes	No	Total
10	36	46

**All 46 respondents answered this question. 10 of the 46 respondents 22% who answered replied they did receive professional support though some indicated that the amount of support was minimal:**

**"A little, not enough."**

**"We had one meeting with a social worker."**

**Only in a family where the father is a doctor was the respondent able to state:**

**"Any we needed was available."**

**Parents who need but do not receive support are isolated:**

**"we were in the system but not supported."**

**and this can cause great trauma:**

**"I reclined into silent shock and the marriage suffered."**

**This last response shows the serious implications that lack of necessary information and can support can have as Woodburn [1977] writes:**

**"At whatever time the diagnosis is first discussed the occasion is crucial for the social prognosis. Helpful information given with understanding, with acceptance of and concern for the parents distress, with ample time to allow them to assimilate the information and above all with the assurance of continuing help, may strongly affect their ability to deal with the total problem."**

**It is possible that if parents had felt themselves to be supported at this early stage they would have been less likely to go outside the 'system' in later years as it has been shown that parents are more likely to comply with the advice of professionals where their own needs had been met [Korsch, Gozzi, Fronen. 1968]. However, only 10 22% families received any support from the professionals at this stage indicating an unsatisfactory level of support at this critical time of diagnosis.**

**Q.B.14. Parents' Perception of Referral for Physiotherapy after Diagnosis.**

**This question sought to establish whether the child was referred for remedial help after diagnosis. Such a referral not only benefits the child physically but also benefits the parents by giving them a sense that something is being done to help their child.**

**All 46 respondents answered this question. One parent of a child with Spina Bifida felt that the question was not applicable but did not clarify why this was so.**

REFERRAL FOR PHYSIOTHERAPY AFTER DIAGNOSIS			
Yes	No	N / A	Total
42	3	1	46

**3 of the respondents who answered 'Yes' elaborated their answers thus:**

**'after discharge at 6 weeks old.'**

**'before diagnosis'**

**'but not immediately.'**

**One of the respondents who answered 'No' elaborated her answer thus:**

'he was already having physio. at the [clinic] but we thought it was as he was delayed with his other disorder neurofibromatosis.'

Of the other 2 respondents who answered 'No' to this question, their answers to subsequent questions established that their children did, in fact, receive physiotherapy. Their negative answer to this question might be explained in 2 of the cases by the delay between diagnosis and the commencement of therapy - 3 months and 24 months- leading parents to feel that their child was not referred for therapy after diagnosis.

The overwhelming majority 42 91% children were stated to have been referred for physiotherapy after diagnosis indicating a good level of response to this need at this time. Parents, initially at any rate, might feel satisfied with this.

**Q.B.15 Parents 'Perception of Time between Diagnosis and Commencement of Treatment.**

This question sought to establish how soon after diagnosis physiotherapy began. As physiotherapy not only benefits the child but also serves to alleviate parental trauma by giving a sense that something is being done, its prompt provision is important.

**All 46 respondents answered this question. The parent of a child with Spina Bifida answered N/A but did not clarify why she thought the question was not applicable.**

<b>TIME BETWEEN DIAGNOSIS AND START OF THERAPY</b>			
<b>Before diagnosis</b>	<b>Within 2 weeks</b>	<b>3 - 4 weeks</b>	<b>5 weeks - 3 months</b>
<b>2</b>	<b>7</b>	<b>13</b>	<b>10</b>
<b>4 months - 6 months</b>	<b>7 months - 9 months</b>	<b>24 months</b>	<b>Total</b>
<b>9</b>	<b>3</b>	<b>1</b>	<b>45</b>

**From once a child is diagnosed and referred for physiotherapy it is important that such therapy should begin as soon as possible, in order to maximise the effect on the children and to minimise the stress that the waiting period would impose on the parents. It is therefore arguable that a reasonable time lapse would be no more than two weeks. Only 7 families, however, received a service that reached this standard, with 23 50% children waiting more than one month for their first physiotherapy appointment. The variation in the lapse between diagnosis and the start of therapy was great - from one day to 24 months, which must reflect both the availability of provision in differing parts of the country and the differing attitudes as to the importance of prompt provision amongst service providers.**

**Q.B.16. Parents' Perception of Regularity of Physiotherapy.**

**This question sought to establish the pattern of frequency with which the children in the survey received physiotherapy as a preliminary to the next question which asks if the parents felt that this frequency was adequate.**

**All 46 respondents answered this question. As 3 of the responses did not fall into the categories used, the total responses in the chart amount to 43.**

FREQUENCY OF THERAPY						
Twice weekly	Once weekly	Fortnightly	Monthly	2 - 3 times monthly	3 monthly	Total
18	4	8	9	3	1	43

**2 of the 3 responses that were not charted noted a reduction in frequency of therapy:**

**'once a week, then once a fortnight'**

**'It started 3 times weekly, then once weekly'**

**and the other child received physiotherapy from two different sources:**

**'once weekly from Spina Bifida physio., once a month National Health.'**

**The correct amount of physiotherapy could be that amount which benefits the child and relieves the parents anxiety about the child, and can therefore vary as between families and depending on the severity of the disability. However a norm might be one session per week. Only 20 43% of children in the survey received therapy this frequently, and 2 4% children received therapy as infrequently as once every two and three months.**

**Q.B.17. Parents' Perception of the Adequacy of the Therapy.**

**This question sought to establish whether, in fact, parents were reassured by the provision of physiotherapy by making a judgement as to the level of its adequacy, for their disabled children.**

**All 46 respondents answered this question.**

<b>ADEQUACY OF THERAPY AS PERCEIVED BY PARENTS</b>		
<b>Yes</b>	<b>No</b>	<b>Total</b>
<b>10</b>	<b>36</b>	<b>46</b>

**10 of the 46 21% respondents answered 'Yes' to this question although 3 of these went on to qualify their answer:**

**'for a while but then my daughter received less physiotherapy.'**

**'As it was all that was available.'**

**'As I didn't understand the great need, I was pleased to accept once a month but later had to complain as she wasn't getting it.'**

**These responses illustrate both the basic willingness of most parents to accept what is offered to their children. Perhaps they indicate also how parents perception of their childs needs changes as they come to learn more about the disability.**

**Of the other 7 70% respondents who answered 'Yes' to this question, 5 were receiving therapy once weekly and 2 were receiving therapy twice weekly. From this and the answers to the previous question, it can be taken that a once weekly therapy session is the least necessary to make a parent feel that provision was adequate.**

**35 of the 36 respondents who answered 'No' to this question elaborated their responses by illustrating how strongly parents felt about this issue and how traumatic they found the deficiencies in the provision as they perceived it.**

**25 69% of these respondents cited lack of frequency as a cause of concern:**

**'not often enough.'**

**'the child was very severely physically handicapped and physio every 3 months wasn't enough.'**

**They felt that it was inadequate to benefit their child:**

**'I felt that if he had more physio he would get greater benefit.'**

**'not enough to see any result'**

**Parents were very aware of the benefits of early therapy and some respondents felt that more emphasis should be concentrated on these early years:**

**'Felt therapy being offered was not enough and on reflection, 8 years down the road, I feel that therapy should have been more intense in the formative years. A more structured programme should have been introduced.'**

**'Feel that more should be given when they are younger'**

**Therapists failed to exploit the resource of the mothers willingness to learn to help her own child which would have benefited the child and reduced the parents frustration:**

**'My little daughter needed physio every day and mother shown how to do it.'**

**'once a week was not enough. It was never explained to us as parents why our child needed physiotherapy.'**

**'Once a month at that age couldn't help as we were not trained properly to do it.'**

**Apart from problems with the frequency of the provision, 8 [22%] of these respondents expressed dissatisfaction with the duration of the therapy sessions:**

**'once a fortnight for 5-10 minutes wasn't enough.'**

**'More, especially group therapy would have helped.'**

**'It took up one whole morning to receive 20 minutes of which a lot of talking took place.'**

**This last response illustrates the lack of awareness than some professionals can show to families of children with disabilities. An increased sensitivity needs to be developed to the difficulties which families experience travelling with a disabled child and to ensure that appointment times are respected to minimize waiting around, and that appointments are of a sufficient duration to make any travel worthwhile.**

**Other respondents questioned the quality of the service which they received:**

**'hopelessly inadequate because no effort made to push the child and no plans made for the child. If the child did not respond, physiotherapist deemed child tired and gave up without motivating the child.'**

**'but [she] didn't know how to treat them'**

**'My child was ataxic only and I know the physio did not know how to handle [her].'**

**Some were unhappy with the way that they were treated:**

**'Too many children waiting to be seen - a conveyer type approach, very little individual attention.'**

**'It was inadequate. A lot of time wasted waiting around for lengthy periods.'**

**5 14% of the respondents who answered 'No' wrote of the effort involved in attending the therapy appointments and they felt that this effort was not justified by the standard or amount of therapy which the child received:**

**'because of distance travelled for three-quarters of an hour of physiotherapy.'**

**'Had to get two buses to hospital and then do the work on the child and sometimes the physiotherapist was not there.'**

**Only 7 15% of respondents were unreservedly satisfied with the adequacy of the therapy service which their child was receiving. For the others rather than having their anxieties relieved by the provision of therapy services the trauma of the majority of parents in this study was increased by its inadequacies.**

### **Summary of Section B.**

**Section B. explored the experiences of the parents at and around the time of diagnosis and early therapeutic provision, to establish how these experiences contributed to or alleviated the trauma that they suffered at this time.**

**In order to minimise trauma parents need a timely and clear diagnosis. Most of the children in this study were diagnosed by the time they were one year old, although 8 18% were not diagnosed until they were over two years of age. In the majority of cases where the disability was not detectable at birth, it was one or both of the parents who first suspected that the child had a problem. Just over half the relevant families felt that obtaining a diagnosis was problematic and approximately one third received an additional diagnosis of a mental handicap which did not exist.**

**The apparently common situation of the parents being aware that their child has a problem while being unable to get a professional to**

confirm or diagnose this problem, is a particularly traumatic one for parents, as it increases their anxiety and can interfere in the establishment of a proper parent/baby relationship. Professional sensitivity to parental concerns is therefore crucial at this stage and it is essential that professionals should not make a rash or presumptive additional diagnosis of a mental handicap. To do so serves to increase parental trauma by alienating parents from the professionals, whose help, they need, and by undermining the trusting relationship that should exist between parent and professional if the child and her family's best interests are to be served.

Of the 46 families who responded to the survey 33 72% of the disabled children were referred to another specialist or agency. 26 78% of these children were referred to the Central Remedial Clinic. If a doctor is unable or unwilling to make a diagnosis of a disabling condition in a child, then such a referral should be done promptly in order to minimise the delay that can exacerbate the trauma suffered by the parents. That such referral is so common also raises questions as to the level of awareness amongst the medical professional in general, and concerning the availability of local services.

Only 5 11% of the responding families did not find the diagnosis of a disability to be a very difficult one. Words such as 'terror', 'pain', 'anger' and 'afraid' give an indication of the rawness of the parents' emotions at this time. Our society in general has little knowledge of those who are disabled and therefore a diagnosis of a disability is a step into an abyss.

**Prior to diagnosis, 38 of the 46 83% families had no knowledge of the condition which affected their child and 2 4% of the other families had only a 'very little knowledge'. Information, then, is a key to the alleviation of the trauma of diagnosis yet only 15 of the 43 35% families who answered the relevant question were offered any information at the time of diagnosis. The great majority of responding families 78% were dependent in whole or in part on personal reading for information on their child's disabling condition. This would suggest that the quality of information received by parents is, in great part, dependent on their ability to access and assimilate it.**

**The large majority of respondents 78% would have liked to have been told about support groups at this stage yet only 13% of families were. Such support groups can play a vital role in relieving parental trauma, not just by providing the vital information, but also by providing formal or informal peer-counselling by other parents who have been through the same process.**

**Only 10 of the 46 [22%] families received any support from the professionals at this stage, while 78% of them felt a need for such support. The majority of professionals then, give a diagnosis without any information as to its nature or implications, without offering any support or even advice as to where they might receive such support; which leaves parents without knowledge, isolated and traumatised. These professionals appear to be still unaware of or unconcerned by the effect that a diagnosis of disability has on parents.**

**For a family traumatised by the actual diagnosis, unsupported by professionals or support groups and possessing only that information which they themselves are able to access or understand, the referral to a physiotherapist is crucial. Not only is a physiotherapist a purveyor of knowledge about their child's disability and a link to the 'professional' world, but the receipt of physiotherapy is an act of faith in the child's potential.**

**Therapy is the means by which the child's condition will be ameliorated. The vast majority 90% of the children were stated to have been referred for therapy after diagnosis or had been receiving it prior to diagnosis and this therapy began as soon as one day after diagnosis and as late as two years after diagnosis. All the children eventually received physiotherapy. 23 50% children waited longer than one month for their first therapy appointment which, in the context of the importance of early therapy, is unacceptable.**

**The frequency of therapy ranged from twice weekly to once every three months with a minority 48% of children receiving therapy on a weekly basis. Only 21% of respondents were satisfied with the therapeutic provision at this early stage. Parents wanted frequent physiotherapy sessions of an acceptable duration within reasonable distance of their homes, by a therapist whom the parents perceived to be competent and caring and who would communicate with them.**

**Therapists are failing to see and use parents as a resource. If therapists worked with parents and taught them a programme of therapy to be carried out daily at home, this would serve to increase the amount of therapy which a child receives. It would also improve**

**the knowledge of the parents, improve the communication between therapist and parent and give parents a sense of purpose.**

**This in turn would decrease the dissatisfaction felt by parents, relieve some of their anxiety and thereby reduce their trauma. The period of diagnosis and early therapy in the survey was characterised by a lack of awareness of, and sensitivity to, the needs of the parents. There was no sense of parents and professionals working together for the child's best interests. Parents were left isolated, without information or support and frustrated by the deficiencies which they perceived in the therapeutic provision. It is unsurprising that these parents prove to be so receptive to Conductive Education.**

## SECTION C

This section sought to establish how much scope there was for a dissatisfied parent to avail of services outside their own area or institution, in an effort to ease their trauma. It also explored the sources of support available to provide for their child and the families at this time and established their perceptions of the adequacies of therapeutic provision and their feelings about any perceived inadequacies.

### Q.C.1. Availability and Use of Alternatives to Local Therapeutic Provision.

This question sought to establish whether parents who were largely dissatisfied [Section B] with the available provision, were able to avail of flexibility within the system by moving from area to area or from institution to institution.

All 46 respondents answered this question.

ALTERNATIVE THERAPEUTIC PROVISION AVAILABLE OR USED					
No	Different therapist	Specialist clinic	Different health board	Different doctor	Total
31	9	4	1	1	46

The majority - 31- 67% respondents did not seek services from outside their own area. 4 29% respondents sought services from a

specialist clinic. Of the 9 20% who changed physiotherapists, 3 families employed a private physiotherapist. In fact there appears to be little parent flexibility in availing of services.

The Health Board system is probably a large contributory factor to this lack of flexibility. Therapy services are provided by the Health Boards which cover very large geographical areas, therefore even if a different Health Board would supply a service [which is unlikely] to a parent dissatisfied with that which they were receiving in their own area, it would be very difficult for parents to avail of this, for reasons of distance, travel and expense. There is very little scope within the system for a dissatisfied parent to seek to compensate for the deficiencies which they perceive.

**Q.C.2. Parents Inclination to Adopt Other Alternative Therapies.**

The purpose of this question was to demonstrate the general stability of the parents in accepting whatever perceived inadequate service was available.

All 46 respondents answered this question.

ADOPTION OF OTHER THERAPIES		
Yes	No	Total
5	41	46

Parents were asked in this question to indicate whether they had ever turned to 'alternative' or 'unorthodox' therapies.

5 11% of the families surveyed turned to such a therapy.

The vast majority of families 89% did not turn to an 'alternative' therapy despite a general dissatisfaction with the level of service [Section B], most parents tolerated it and tried to make the best of it. They show no tendency to chase 'miracle cures.'

### Q.C.3. Reactions of Professionals to Use of Alternative Therapies.

This question sought to establish the degree of professional flexibility in accepting a parent's decision regarding their children's therapy needs. It also explored the relationship between parents and professionals in such circumstances.

10 of the relevant 15 respondents answered this question. It is not clear why the others did not answer.

PROFESSIONAL REACTION TO PARENTS AVAILING OF OTHER PROVISIONS				
Disapproving but tolerant	Accepting	Unaccepting	Withdrawal of services	Total
4	3	2	1	10

**It was established in Q.C.1. that 15 33% families made some alteration to their child's therapeutic circumstances 'within the system'. 10 of these respondents answered this question C.3.**

**3 30% of these respondents found the professionals accepting of their decision. The other 7 70% experienced lack of acceptance, lack of approval, and in one case, the withdrawal of services.**

**Q.C.2. established that 5 11% families turned to an 'alternative' method of therapy. 4 of these 5 respondents answered this question C3. One of the families decided not to tell the professionals of their decision and the other 3 had their child's services withdrawn by the professionals.**

**In general there is evidence of a deal of inflexibility on the part of professionals who seem intolerant and disapproving of parents who seek services outside their own areas or who attempt alternative therapies.**

**Parents who feel the need to look elsewhere for services might do so in the interest of their child and therefore would benefit from a supportive and tolerant reaction from the professionals rather than negativity which might serve only to compound an already frustrating situation.**

**The most serious undermining of the parent/professional relationship happens when a professional punishes a child for the parents' perceived dissent by withdrawing State resourced services from that child. Thus parents who seek to improve their children's position with regard to therapy can find themselves being deprived of the**

therapy which they had been receiving. This could have serious physical consequences for the child and places the parents under a considerable extra stress.

**Q.C.4. Parents' Perception of other support received.**

This question sought to establish where the necessary support was coming from to help the family given that it has been shown [Section B] that none appeared to be available from professional sources.

45 respondents answered this question. 1 respondent felt that this and the next three question were not applicable to them, and there is no obvious reason for this.

As some families received support from more than one source the question gave rise to 81 responses..

OTHER SUPPORT RECEIVED BY FAMILIES						
Family	Extended family	Friends	Community Organisations	None / hardly any	N / A	Total
34	17	18	5	6	1	81

One respondent drew the distinction between support which they received from family, and other help, which the family were unable to give. This answer probably indicates the respondents desire for professional help.

5 of the 45 11% respondents received very little or no support at this time and of the 40 87% who did receive support, the majority 41 64% received some or all of their support from family and extended family. While all support is important to the parents this informal support cannot be professional in the sense that it cannot prepare, help or support parents in progressing an adequate, professionally acceptable, educational and family situation for their child.

**Q.C.5. Parents' Perception of the Quality of Therapy.**

This question sought to ascertain the parents' perception of the quality of the therapy which their child was receiving in order to establish whether or not it was satisfactory to them.

45 respondents answered this question. However as 1 response did not fall into any of the categories, the total charted responses is 44.

QUALITY OF THERAPY AS PERCEIVED BY PARENTS						
Very good	Good	Satisfactory	Poor	Very poor	N / A	Total
3	4	7	16	13	1	44

29 66% of respondents did not feel that the quality of therapy which their child was receiving was satisfactory, which placed them in the situation of seeing their child deprived of a service which they considered adequate to maximise the child's potential.

**3 respondents elaborated their answers:**

**'satisfactory until school age'**

**'satisfactory - just about'**

**'poor and very poor'**

**The response which was not categorised in the chart marked the difference between the quality of the State provision and that available from a private physiotherapist:**

**"Private physio. very good. Health Board physio. very poor."**

**One respondent answered that the question was N/A although they did not clarify this response.**

**The responses to this question progresses the emerging pattern of the majority of parents being dissatisfied with the therapeutic provision which their child was receiving.**

**Q.C.6. Parents' Perception of the Effectiveness of the Available Therapy.**

Having established the perception of satisfaction with the level of therapy in the previous question, this question sought to ascertain its effectiveness as perceived by the respondents. A parent's estimate of the effectiveness of locally available services would be an important factor in the parents' deliberations about turning to Conductive Education.

45 respondents answered this question. 1 response could not be tabulated and therefore the total charted responses amounted to 44.

EFFECTIVENESS OF AVAILABLE THERAPY					
Very effective	Effective	Fair	Ineffective	Totally ineffective	Total
0	7	13	18	6	44

The response which was not tabulated drew the distinction between State provision which was deemed to be 'totally ineffective' and private provision which was considered to be 'very effective.'

If parents had been very satisfied with the effectiveness of the therapy their child was receiving then they would hardly have needed to go away to find another service at great personal cost to themselves. In actual fact no one found the service very effective, only 7 16% found the service effective, and about twice that number found it fairly

effective. 25 54% of respondents found it either ineffective or totally ineffective.

This would seem to indicate that a majority of parents had a poor opinion of the effectiveness of the available services, and it is therefore not surprising that they should in the future turn to a method which they perceive to be more effective.

**Q.C.7. Parents Feelings about the Services Available to their Children.**

This question sought to establish how parents felt prior to turning to Conductive Education about the services which their child was receiving. Feelings of satisfaction or frustration would be a powerful motivation in any deliberations about seeking an alternative.

**45 respondents answered this question.**

PARENTAL FEELINGS ABOUT THERAPY SERVICES						
Very happy	Happy enough	Tolerant	Frustrated	Very angry	Other	Total
2	4	10	21	7	1	45

**28 62% parents felt either frustrated or very angry with the services available to them. One respondent wrote that they felt:**

**'very angry and very worried.'**

**The frustration of one of the respondents could have been relieved by proper communication between herself and the professional:**

**'frustrated as I got a set of exercises to do every Monday to practise all week, no-one explained why.'**

**and another respondent was resentful about the perceived lack of commitment of the therapist:**

**'I feel that it is really up to parents to do the work on the child, but it would be helpful if professionals did a proper day's work.'**

**A small proportion, one eighth, were either happy or very happy while close to one fifth felt that the services were tolerable. There appears to have been a high and proportionally powerful level of frustration and anger in the group as a whole. This would constitute a strong determinant in any decision making about alternative therapies.**

**Obviously the same set of parents who felt positively about the service also seem to judge it to be effective and also rate it 'good' or 'very good'. This could be explained either by an unusually good service being available to some parents or by low expectations on the part of**

**those parents; on the evidence it is difficult to say which of these two conclusions might be more appropriate.**

### **SUMMARY OF THE FINDINGS OF SECTION C.**

**Section C. provides us with a kind of snapshot picture of the families as they might be just before making the decision to turn to Conductive Education.**

**Most of the families continued to receive services in their own area and very few [5] had tried an alternative therapy. Those however, who did turn to other methods, and who informed the professionals were 'punished' by having their local services withdrawn. This sanction was also used against a family who turned to a different therapist.**

**The great majority of families received most support at this time from family and extended family although 5 families received little or no support from any source at this time.**

**Questions C.5, C.6 and C.7 gave us a picture of the state of families vis á vis available therapies. The majority thought that the level of therapy received by their children was less than satisfactory, that it was ineffective in helping them with their child's handicap and that it was leaving the great majority of them frustrated and/or angry.**

**The level of dissatisfaction and frustration being experienced by the parents would seem to leave them very open to the attractions of an alternative therapy. Yet that these parents are not inveterate 'rebels' or 'non-conformists' can be seen by the fact that so few of them went outside the system prior to taking on Conductive Education.**

#### **SECTION D.**

**Section D seeks to explore the details of the families' involvement with Conductive Education. It looks at all areas from the initial hearing about Conductive Education, to an assessment of the perceived value of Conductive Education both before and after involvement and at the reactions of the professionals who were dealing with the children at home.**

**It should be noted that five of the families who responded to this survey had never attended the Peto Institute in Budapest. Instead, they had availed of pilot projects and summer camps at home and abroad which employed Hungarian Conductors. Their contribution to the survey was nevertheless considered valuable, as all their experiences, short of attendance at and travelling to the Peto Institute in Budapest, mirrored that of those who actually travelled to Budapest. These parents answered questions relevant to their experience. They were therefore unable to answer questions which directly related to experiences of travel to Budapest and experiences of the Peto Institute in Budapest, although some adapted the questions to reflect their situation and comment on Conductive Education as they experienced it.**

**Q.D.1. Parents' First Contact with Conductive Education.**

**This question sought to establish whether there was some pattern in the way the Conductive Education first impacted on parents.**

**All 46 respondents answered this question. As some parents first heard about Conductive Education from more than one source this question produced 54 responses.**

<b>FIRST CONTACT WITH CONDUCTIVE EDUCATION</b>				
<b>Standing up for Joe</b>	<b>Media</b>	<b>Friends</b>	<b>Professional Advice</b>	<b>Total</b>
<b>21</b>	<b>14</b>	<b>16</b>	<b>3</b>	<b>54</b>

**A little less than half the respondents 21 45% saw the documentary film 'Standing up for Joe' and most of the others heard about it from friends or other parents. Some respondents saw a newspaper item on the T.V. or read about it in newspapers or magazines. Only a few respondents first heard about Conductive Education from professional sources - through physiotherapists or through involvement with a pilot group.**

**Thus the film had the most powerful impact and seems to have been a high motivator. This documentary film, 'Standing Up For Joe', was screened in April 1986. It focussed on Joe Horsely who was severely disabled by Cerebral Palsy, and followed his family as they travelled to Budapest to have Joe assessed for suitability for admission to the Peto Institute. It showed the provision which was available to him at**

home in England, which while caring, was not working to maximise the physical potential which his parents felt existed. This provision was contrasted with the provision available in the Peto Institute which was characterised by stimulation and positivism. Few documentaries have provoked such a response as this one. After the programme finished the B.B.C. received over eleven thousand phone calls and many more were received by the Hungarian Embassy. Obviously, Conductive Education as portrayed on this film aroused widespread interest and concern that a new and practical approach to Cerebral Palsy and Spina Bifida was available.

**Q.D.2. Reasons Why Parents Felt that Conductive Education would be Effective in Helping their Child.**

This question sought to establish whether the parents' perception of Conductive Education's effectiveness had common identifiable factors.

43 respondents answered this open-ended question and their answers can be classified into 51 responses. There is no apparent reason why one of the respondents did not respond but the other two families had not travelled to Budapest and possibly felt that they were therefore excluded.

The most commonly cited reason 13 30% why parents felt that Conductive Education might be effective in helping their child was a

**sense of dissatisfaction with what was available at home. Parents felt that:**

**"Because the only other available physio service was inadequate."**

**"Anything was better than nothing."**

**"It was worth a try as it couldn't be worse than he was getting in this country."**

**This feeling that it was 'worth a try' was reflected in 12 28% of answers:**

**"At this stage we were prepared to try any method which may have been an assistance."**

**"Worth a try, I had an open mind on its benefits."**

**2 5% respondents stated that their feeling that Conductive Education might be effective was based on their knowledge of the method:**

**"I had heard a lot about C.E. and thought why not try it."**

**while 1 respondent knew nothing about it:**

**"I did not know what it was, but thought that surely there was something else I could do for my son."**

**1 respondent did not have any feeling that Conductive Education might help her child:**

**"I didn't. But I was willing to try anything that might help give our son a better quality of life than a wheelchair."**

**The feeling that it was worth a try and must be better than what was available at home was also a factor affecting the decision of the 37% of respondents who cited desperation as a strong determinant:**

**"Because at the time I was desperate."**

**"When you are desperate you will try anything."**

**1023% of responses indicated that parents felt that they would achieve good results from Conductive Education:**

**"Seemed to be the best chance that she would walk."**

**and that it offered hope of achievements:**

**"A lot more hope that she would walk and have as near as possible a normal life."**

**1 respondent was attracted by the pleasant atmosphere and 49% by the positive approach or the expertise or dedication of the staff:**

**"The positive attitude was striking."**

**"It was so positive and I was not happy with the treatment she was getting."**

**The reputation of the Institute attracted 3 7% respondents:**

**"Because of the excellent results claimed.",**

**one went on the advice of a professional who felt that the child would benefit; and one because of how well the child performed in a pilot group in which she was involved at home.**

**The method, particularly its use of groups and the intensity of well structured therapy led 9 21% of respondents to feel that Conductive Education would benefit their children:**

**"Because it offered a group service as opposed to the child going solo and it was a structured programme every day."**

**"Because of the amount of physiotherapy he would be getting every day."**

**3 7% respondents felt that Conductive Education would help them to better help and understand their child:**

**"I needed to know more about him."**

**and one of these also noted the 'hope' that it gave them:**

**"Also gave great hope - not available from anyone in Ireland."**

**The answers which the respondents gave to this question confirm emotions and circumstances of the families as established in Section C. of the questionnaire. Parents had become disillusioned and frustrated by both the lack of quality and the infrequency of the therapy provision at home and were attracted to Conductive Education by the contrast which it offered in the frequency and intensity of the therapy. Similarly the desperation that many parents felt contrasted with the hope and positivism offered by Conductive Education.**

**Q.D.3. Parents' Perception of the Comparison between the Treatment at the Peto Institute and that Available at Home.**

**This question sought to establish a parental comparison between Conductive Education and the therapy received at home and to quantify the perceived differences in quality and intensity of work done in either case.**

**41 respondents answered this question, and as some respondents indicated more than one answer, it produced 68 responses.**

**5 respondents to this survey never travelled to the Peto Institute in Budapest. 4 experienced Conductive Education in Northern Ireland,**

Wales and Dublin and 1 family brought a Conductor to Ireland without ever attending the Institute.

2 of these respondents did not answer any further questions from this point. The other 3 respondents continued to answer those questions which pertained to Conductive Education rather than specifically to the Peto Institute or Budapest. As the Centres which they attended were staffed by Hungarian Conductors, they were also able to comment on the qualities of those Conductors who worked with their children.

The total responses to all further questions will therefore vary accordingly.

PERCEIVED COMPARISON OF TREATMENTS				
Highly Professional approach	Much better understanding	Better method	Same but more intensive	Total
15	21	23	9	68

Most parents perceived the Peto approach as qualitatively different as regards professionalism, understanding and method, although their answers to this question would be somewhat coloured by their subsequent confirming experiences. It would also seem that they felt that the Peto approach was based on a better understanding of their own needs and their child's needs. One parent wrote that:

**"It was like coming home."**

Since the only information that many of these parents had at an early stage about Conductive Education was that gleaned from a single documentary, it could be that this is actually a statement of the defects that they perceived in the provision that they were receiving. What the parents were therefore saying is that the provision which they were receiving lacked professionalism and understanding and intensity and that they were implicitly searching for a better method which Conductive Education seemed to supply.

Q.D.4. Parents' Perception of the Most Compelling Motive for Turning to Conductive Education.

*This question sought to establish the principal motivating factor behind the decision to turn to Conductive Education on a spectrum ranging from positive to negative motivation.*

43 respondents answered this question and there is no obvious reason why the respondent who did not answer failed to do so.

Although respondents were asked to indicate their MOST compelling reason for turning to Conductive Education only twenty-eight restricted their answer to a single reason. Therefore the 44 respondents produced 67 responses to this question.

MOTIVATION FOR TURNING TO CONDUCTIVE EDUCATION					
Great hope for child	Slight hope for improvement	Dissatisfaction with present system	Guilt	Desperation	Total
20	16	18	4	9	67

**In hindsight this question should in fact have been two questions - one with a positive scale and one with a negative scale as all but one of the respondents who indicated multiple responses did so in order to reflect the duality of the basis of the reasoning.**

**This duality is clearly illustrated by the fact that 'great hope for the child' was cited by 20 30% of respondents and 'dissatisfaction with the present system' was the next most commonly cited motive indicated by 18 27% of respondents. 16 24% of respondents cited 'slight hope for the child', 9 14% cited 'desperation', and 4 6% cited 'guilt'.**

**All but one of the fifteen respondents who indicated more than one response showed in doing so that their motivation had both a positive and a negative aspect - some level of hope for their child combined with dissatisfaction, guilt or desperation about their situation.**

**Parents, then, were motivated to turn to Conductive Education both because it offered them hope for their child and because of their negative perceptions of their existing position.**

**Q.D.5. Parents' Perception of Family Support for the Decision to go to Budapest and the Peto Institute.**

**This question sought to establish if, in the absence of official support, the parents received any family support for their decision to turn to Conductive Education.**

**44 respondents answered this question. The 3 families who had not travelled to Budapest interpreted this question as to relate to support for their decision to turn to Conductive Education.**

<b>FAMILY SUPPORT FOR DECISION TO TURN TO CONDUCTIVE EDUCATION</b>				
<b>No family support</b>	<b>Fair family support</b>	<b>Good family support</b>	<b>Fullest family support</b>	<b>Total</b>
<b>1</b>	<b>2</b>	<b>17</b>	<b>24</b>	<b>44</b>

**All except three of the respondents received good or fullest support for their decision from their families.**

**It was established in Q.A.2. that the overwhelming majority of the respondents were married and could therefore be supposed to be in a stable family situation. Given this stable nuclear family and the common Irish situation of an extended family, the respondents would seem fortunately endowed with support and assistance. The decision made by these families was a complex and difficult one which involved a rejection of the State system, the separation of families, a large financial commitment and a resolution that one parent and the disabled child would live in a foreign country for periods of time. The**

existence of good or fullest family support must have given the respondents great confidence in the correctness of their decision, and confirmed their purpose in carrying it out.

**Q.D.6. How Parents Financed their Visits to Budapest and the Peto Institute.**

This question sought to establish whether the financial implications of the decision to turn to Conductive Education imposed much extra hardships on the families.

41 respondents answered this question but as 6 of them financed their visits through more than one means, this produced 47 responses.

While there is no obvious reason why 2 respondents did not answer this question, it is appreciated that questions related to finances might be considered sensitive.

FINANCING OF VISITS TO PETO INSTITUTE						
Fund-raising	Private savings	Borrowed	Sold property / business	Family	Other agencies	Total
30	10	2	2	2	1	47

Given that even a one month visit to the Peto Institute in Budapest would cost several thousand pounds it is not surprising that 30 of the families 30 73% relied on fund-raising to some extent. 25 61% of the families fundraised or had money fundraised for all their visits.

**Two families borrowed money and then fundraised, and three families used their own finances and then fundraised. Two respondents were helped financially by their own families. One respondent replied that they:**

**"sold business [a pub]"**

**and one that they:**

**"sold nearly everything we could and then started a fund"**

**Thus the support which existed for these families made it possible to have funds raised to finance the visits to Budapest. Given the expense involved it is likely that many, if not most, of these families would not have been able to commit themselves to their decision without this support.**

**Q.D.7. Parental Perception of Support from their Local Community.**

**This question sought to establish if family support offered by families was supplemented by practical voluntary and community support.**

**All remaining 44 respondents answered this question.**

PERCEIVED COMMUNITY SUPPORT		
Yes	No	Total
35	9	44

**1 family specified that this was 'fund-raising support.' As 25 of the respondents to Q.D.6. stated that their visits to Budapest were wholly or partially financed through fund-raising, it is likely that this was the most common practical way in which communities became involved.**

**The majority of respondents, 35 83%, received support from their communities. This indicates a high degree of responsiveness in communities to parents' distress, and a great willingness to help and become involved with individual disabled children and their families. It shows that when parents develop their own conviction that something can be done to help their child, and statutory agencies offer no help and even act as a disincentive, individuals and communities are far more perceptive in facing what needs to be done by positively contributing to the overall effort.**

**Q.D.8. Frequency of Visits to Budapest.**

**This question sought to establish how many times families may have visited Budapest, with a view to seeing whether perceived results might justify returning frequently.**

**38 respondents answered this question. Apart from the 5 respondents who did not travel to Budapest, this question was also not answered by the 2 families who were in Budapest on a long-term basis or by the 1 family who brought a Conductor to Ireland on a long-term basis.**

FREQUENCY OF VISITS TO BUDAPEST		
1 - 2 trips	3 - 5 trips	6 - 11 trips
14	20	4

**24 63% respondents had returned to Budapest at least three times at the point at which this survey was taken. The decision to go to Budapest in the first place is often categorised by professionals as a flighty or whimsical one. But given the hardships involved, the decision to return must have been based on a belief that the results being achieved justified the effort.**

**2 children attended the Institute on a full time basis:**

**"Dora lived there for 2 years - many trips."**

**"We spent in all three years in Budapest."**

**This was an opportunity available only to the very first Western families to attend the Institute.**

**1 respondent answered that they had a private Conductor for two years and this was an issue that caused some controversy at the Peto Institute in the earlier years. Many parents from the 'West', particularly the U.S., Australia, and England brought Conductors back with them to their homes for prolonged periods.**

**Conductors were quite badly paid in Budapest even by Hungarian standards, and many were very willing to leave the Institute for the 'West' and earn Western rates of pay. The advantage to the families concerned was obviously to have Conductive Education in their own homes. However this practice depleted the Institute of Conductors to what was at times critical levels, leading to complaints from other parents about the size of the groups and the Conductor/child ratio at the Peto Institute. This impacted not only on the Western children attending the Peto Institute but also on the Hungarian children. This practice was also objected to because one of the pillars of practice upon which Conductive Education is based is group work.**

**5 13% respondents also indicated that they had employed a Conductor at home during various school holidays. This was initially disapproved of by the Institute but was later placed on an official and formal basis by them. This had the advantage to the families of allowing the child to remain at school during term-time while benefiting from the individual attention of a Conductor during school**

holidays. It was also cheaper to have a Conductor at home for a month than to travel to and stay in Budapest. It also had the important advantage that it avoided the necessity of separating families.

**8** 21% families also experienced Conductive Education in Summer Camps or in centres in Northern Ireland. Summer camps have become an increasingly popular way for families to give their children the advantages of Conductive Education with minimal expense and disruption to their families. These are organised by parents who will bring two or more Conductors to Ireland to work with groups of children in places such as school halls. Apart from the fact that costs are shared this option is preferred by many parents because the children work in groups as they would in Budapest.

Two centres now exist in Northern Ireland on a year round basis, offering short and long-term places to children wanting Conductive Education. **7** 18% respondents to the question have been to one or both of these centres -one child attended there five times, one attended six times and one child stayed there for a period of ten months.

Thus, parents have shown a determined commitment to Conductive Education. The majority of respondents to this survey have returned to Budapest repeatedly despite the privations involved. These same families and others have circumvented many of the privations by

**adapting and importing Conductive Education into Ireland and by availing of the more proximate opportunities of to experience it. The phenomenon of parents importing a therapy into Ireland to work outside the existing provision is an unprecedented one.**

**Q.D.9. Duration of Visits to Peto Institute.**

**This question sought to establish the number of visits to the Peto Institute that were of a short duration as compared to those of a long duration.**

**The cost and effort required to travel to Budapest would suggest that a visit of a longer duration would be more worthwhile. However, because of pressure on places at the Peto Institute most families would not have been invited to stay for longer periods.**

**38 respondents answered this question which is consistent with the response level of the previous question.**

DURATION OF VISITS TO PETO INSTITUTE		
1 month or less	5 weeks to 11 weeks	3 months or more
88	48	15

**The responses to this question show that most children experienced Conductive Education for short periods at any one time. Of the total**

of 151 recorded visits 88 58% were of a duration of one month or less. Only 10% of visits were for a period of three months or more.

The fact that so many parents opted even for visits of short duration is significant, in that it shows the degree of their commitment to Conductive Education and the perceived benefits which they got even from a short stay. Many parents returned three or four times for visits of two or three weeks duration.

**Q.D.10. Parents' Perception of the Difficulties of Travel to Budapest.**

This question sought to establish how families felt about the journey to and living in Budapest and to find out what parents were prepared to endure in order to realise their hopes for their child.

41 respondents answered this question reflecting the number of families who had actually travelled to Budapest.

PERCEIVED DIFFICULTIES IN TRAVELLING TO BUDAPEST					
Extremely arduous	Difficult	Bearable	Pleasant	Very enjoyable	Total
4	16	9	6	6	41

9 22% found the experience bearable, and 12 30% found it pleasant or very pleasant. However 20 49% experienced difficulty.

**It is unsurprising that parents should vary in their reactions to the experience of travelling to and staying in Budapest. Some adults and children are more naturally adjustable and more adventurous than others. Parents with less severely disabled children would probably find the experience less arduous than those with more severely disabled children. One respondent differentiated between the travelling and the stay:**

**"Travelling difficult, stay pleasant."**

**2 respondents stated that subsequent trips became easier:**

**"First trip very difficult. Subsequent trips bearable and eventually pleasant."**

**"At first difficult, second visit more pleasant and last two visits, pleasant."**

**This could be attributable either to the fact that parents were more knowledgeable on the subsequent trips or to the fact that the 'Iron Curtain' began falling in 1989/1990 and its effects were felt immediately in Hungary. Therefore a lot of the pressure caused by living in an Eastern Block country disappeared. Also in 1987 the British Embassy in Budapest established a Community Centre for 'Peto Parents' which helped to establish a sense of community and support between the families out there.**

**Robinson et al [1989] suggested that the primary benefit to families who travelled to Budapest derived from the 'pilgrimage effect', part of which he suggests:**

**"may derive from the distance concerned as well as the effort in getting there."**

**But most parents would feel that this is insulting. The 20 46% of families who continued to travel to Budapest despite finding it arduous or difficult shows a particular commitment to Conductive Education and the results it was achieving.**

**Q.D.11. Parents' Perception of the Degree of Professionalism of the Staff at the Peto Institute.**

**This question sought to establish how parents would assess the abilities of the staff at the Institute. This perception would have implications vis a vis the perceived professionalism of those at home.**

**42 respondents answered this question. 1 of these respondents had not attended the Peto Institute but commented on the Conductors with whom her child had worked in other centres.**

PERCEIVED PROFESSIONALISM OF INSTITUTE STAFF					
Highly professional	Very skilful	Knowledgeable	Attentive but not very good	Good but not very attentive	Total
20	12	6	0	3	41

**The responses to this question show an overwhelmingly positive perception of the abilities of the staff at the Peto Institute although this was not unanimous and some respondents were critical. One respondent felt that while some of the staff were good, others did not meet the same standard:**

**"Some highly professional, very skilful and very knowledgeable, very variable, others were poor and not interested."**

**Two other respondents noted a decline in the standard of professionalism as time went on:**

**"highly professional, very skilful, and knowledgeable. But as time went by, staff attitude changed."**

**"One time highly professional, then not very good."**

**2 of these respondents who were critical had visited the Peto Institute on three occasions and one respondent who had noted a decline in**

standards had spent two years there. They were therefore well placed to observe any such decline.

Prior to 1986 the Peto Institute had been the National centre for the education of Motor Disordered children in Hungary and catered for few non-Hungarian children. After the BBC documentary they were inundated by tens of thousands of parents from all over the world who all wanted their children to be given a place at the Institute. This great pressure from parents plus the enormous amounts of hard currency that they were prepared to pay for their child's place led to accusations that group sizes were growing and staff/child ratios increasing to an unacceptable standard.

This situation was exacerbated by the practice of 'poaching Conductors' - whereby Western families would make contact with individual Conductors at the Institute and then offer them employment in their home country. As all families who wished to employ a Conductor in this way preferred the most experienced one which they could get, there were accusations from families attending the Institute that the groups were increasingly being led by inexperienced Conductors. This issue arises again in some of the responses to the next question.

**Q.D.12 Parents' Perceptions of the Biggest Disadvantage of the Peto Institute.**

**This open ended question sought to establish the respondents' perception of the greatest disadvantage of the Institute. This gives another perspective on how much parents had to endure in order to enhance their children's therapy and of how they perceived the therapy.**

**41 respondents answered this question reflecting the number of respondents who had attended the Peto Institute. The replies can be broken down into 51 responses covering various areas of concern.**

**The most commonly expressed disadvantages arose from difficulties caused by distance, isolation and the splitting up of families 17 41%:**

**"Disadvantage of Budapest, not Institute - being away from home, splitting up family."**

**"Being so far away from your family and friends one felt very isolated."**

**"Having to travel to Budapest and, particularly as child got older, having to separate child from family and friends at home for long periods."**

**1 respondent wrote of how the parents in Budapest helped each other to alleviate some of these difficulties:**

**"from a personal point having to leave family behind and then coping alone - although support from other parents was tremendous"**

**5 12% of respondents cited the journey as a biggest disadvantage and 10 25% cited the language barrier:**

**"The journey to Budapest, also the language barrier."**

**"Lack of English speaking but that's all changed now."**

**Several internal problems in the Institute were mentioned by respondents. 8 respondents 19% cited the size of the groups, overcrowding or the staff/child ratio as sources of dissatisfaction:**

**"Ratio of Conductors to children too low."**

**"size of groups, ratio of Conductors to children"**

**"too many in each classroom."**

**1 respondent felt that the overcrowding situation has improved but indicated where she felt that the root of the problem lay:**

**"At one stage there were too few Conductors to children but now that has improved. Unfortunately we in the West have 'poached' the best Conductors over the years."**

**However another respondent laid the blame for the internal problems firmly within the Institute:**

**As it became famous, it became crowded and greedy for money and less professional and caring."**

**2 5% of respondents were concerned about injuries which their children suffered while in the Institute:**

**"The children were treated too roughly, his knees were bleeding all the time."**

**"My daughter fell in Peto and had 6 stitches in her head. They did not tell me she had a bad bang to her head until I asked why she had steel clips in her head. They tried to brush it off but I only wanted to know what had happened."**

**The expense involved in going to Budapest was perceived as the biggest disadvantage in 3 7% cases, coupled with loss of earnings for one of these respondents.**

**2 respondents 5% felt that the length of time which they were able to spend at the Institute was too short:**

**"Two months was too short a time as it took a couple of weeks for the child to settle in, she was just getting into her stride when she had to leave."**

**1 respondent expressed how misleading she felt that the 'Standing up for Joe' film had been:**

**"I also think the film "Standing up for Joe' gave a very wrong impression. After seeing Joe myself, film portrayed something totally different."**

**This was a very commonly expressed opinion among parents in Budapest. The film gave the impression that Joe had great potential for physical progress and was indeed on the way to achieving such progress. However on seeing the child, who has been attending the Institute full time since 1986, few parents were able to discern any significant progress at all. Discussing this apparent lack of physical progress with a Conductor recently this researcher was told that Joe developed severe epilepsy after arriving in Budapest and that this impeded his hoped-for progress.**

**1 respondent saw the lack of medical training among the Conductors to be a disadvantage:**

**"The lack of medical training among Conductors who made the decisions in accepting the children."**

**4 10% of respondents could see no disadvantage to the Institute with 1 of these attributing this to the group to which her daughter was assigned:**

**"Personally I did not see any disadvantages for her because she was in a special class for ataxic kids. I feel we got the utmost from Peto because her class was so good."**

**The group to which a child was assigned was a very significant factor. Each group worked independently of all other groups within the Institute and the quality of the group depended on the quality of the group leader and her team of Conductors and also, many parents felt, on the number of children in any one group.**

**The range of perceived disadvantages to the Institute was wide, focusing on personal hardships for the parent and the child, language and internal problems within the Institute. A number of respondents 4 10% found no disadvantage with the Institute at all.**

**Q.D.13. Parents' Perception of Actual Benefit Derived from Peto Institute in Comparison with Expectations.**

**This question sought to establish the extent to which the Institute lived up to the parents expectations.**

**40 respondents answered this question. 2 respondents who had been to Budapest did not answer this question for no apparent reason. 1 respondent whose experience of Conductive Education had been outside Budapest took the opportunity to comment on the Conductive Education which they had experienced. 4 respondents who had not been to Budapest did not answer this question.**

PARENTAL SATISFACTION WITH INSTITUTE					
Very badly	Badly	Fairly well	Well enough	Very well met	Total
0	0	7	9	24	40

**In no case did the Institute fail to live up to the expectations of the parents. Each respondent's expectations were, at the very least, met fairly well and in the majority of cases 29 71% were met very well. The responses to Q.D.4. indicated that the most common compelling motives for turning to Conductive Education was 'great hope for child' and 'dissatisfaction with present system' [57%] with 'slight**

hope for the child' [34%] being the next most common. It can therefore be assumed that the Institute provided the parents with an alternative system to the one at home and lived up to the parents hope for their child to some considerable extent.

**Q.D.14. Parents' Perceptions of the Positive Benefit to the Child from Attendance at the Institute.**

This open-ended question sought to establish what the parents perceived to be the greatest benefit their child derived from Conductive Education. It is a perceived assessment or evaluation of how the child improved as a result of Conductive Education.

40 of the remaining 44 respondents answered this question and their replies produced 63 responses. It is not clear why 2 of the 4 respondents who failed to answer did not do so. The other 2 were among those who had experienced Conductive Education outside Budapest. 1 other parent who experienced Conductive Education

**outside Budapest adapted the question to comment on the Clinic which their child attended.**

**Parents were asked to state in what particular way their child benefited from Conductive Education.**

**The overall level of responses was very positive. 27 68% of responses marked physical improvements indicating clear behavioural changes:**

**"She walked in on her knees and walked back into Ireland on tripods."**

**"He went totally confined to a wheelchair, now he is on tripods."**

**"His balance, walking and sitting was corrected within two weeks."**

**Many of the physical improvements were obviously measurable and properly categorised:**

**"Toilet trained, sitting alone, improved head and trunk control, speech, improved grasp."**

**Some very pertinent responses compared the improvement with what was possible at home:**

**"Came home walking on two sticks. Had them here but no-one could teach her to use them."**

**"She came home walking on tripods - prior to going out she could not even sit up."**

**2 parents commented on the child's willingness to work hard:**

**"He learned how to work a long day through the long intensive hours."**

**These long hours are credited in 2 5% of the responses for some of the improvements:**

**"The intensity of the treatment. Obviously if someone spends 6 hours a day on a child there has to be some changes."**

**4 respondents 10% indicated that the work rate and improvement continued after the child returned home.**

**3 8% of responses indicated that the parents had benefitted from the work pattern**

**"I learned how to work with my son."**

**Another noted how:**

**"Our confidence increased."**

**20 responses 50% indicated improved emotional conditioning with epithets like 'enormously', 'a lot', 'more and more' being used to indicate the degree of improvement. Thus 'independence', 'confidence', 'motivation', 'positive attitude', 'enjoyment of work', figure highly in the responses. This aspect of improvement allied to**

**the marked behavioural changes can be illustrated by the response of one parent who wrote:**

**"The constant motivation. Daily therapy, encouragement. She worked very hard but loved every day of it especially as she walked there for the first time."**

**The holistic approach of the method was noted by parents as too was the positive approach of the operation:**

**"The positive attitude at the Institute gives the child and parent so much hope and desire to work. She is now virtually independent at home and at school walking with sticks. She is regarded by the professionals here as being moderately, severely handicapped."**

**"While he was there he was treated with affection and respect. Mostly anything a child could do was lauded."**

**1 respondent wrote that the major benefit which their child derived from their visit to Budapest was that a hip displacement was discovered which:**

**"We did not know or were not informed about in Ireland."**

**2 5% of respondents felt that their children did not derive any benefit from treatment at the Institute though 1 of these felt that this was because they were not there for long enough. Another respondent noted an improvement in her child's toilet training and speech:**

**"but wasn't there long enough due to lack of funds."**

**1 respondent whose child received Conductive Education in both Budapest and Dungannon gave a comparison between the two Institutes:**

**"Child did better in Budapest than in Dungannon where the cost was outrageous. £375 sterling for work alone weekly and £125 sterling for flat, food and taxis. She stayed in Dungannon for 10 months in 1993."**

**The issue of a possible decline in standard at the Peto Institute was raised again in one answer to this question. Her child did:**

**"very well to start with but after two visits I thought they got too greedy for money and started packing up the classroom."**

**Q.D.15. Parents' Impression of General Improvement in the Child's Physical Condition.**

**This question sought to quantify the intensity of the parental conviction concerning the child's improvement.**

**43 respondents answered this question. It is not apparent why 1 respondent failed to do so.**

PERCEIVED IMPROVEMENT IN CHILD'S CONDITION					
Not at all	Hardly	More or less	Definitely	Very much so	Total
2	3	8	20	10	43

**43 respondents answered this question with 5 12% noting little or no physical improvement. 3 8% of the 39 respondents to the previous question stated that their child derived little or no benefit from the Institute. 8 19% of respondents felt that their child's physical condition had 'more or less' improved and the majority 70% reported a 'definite' or 'very definite' improvement.**

**Q.D.16 Parents' Conviction Concerning how they Themselves were Better able to Cope with their Childs Disability as a Result of Conductive Education.**

**This question sought to establish whether involvement with Conductive Education increased the parents confidence in their ability to manage their child's disability. Any such increase in confidence would lead to a decrease in the trauma which they may have been experiencing.**

**All remaining 44 respondents answered this question.**

IMPROVED PARENTAL ABILITY TO COPE					
Not at all	Hardly	More or less	Definitely helped	Very much so	Total
1	1	8	22	12	44

**These responses are very consistent with those of the previous question. One respondent elaborated her answer by stating:**

**"very much so and not so much guilt because something at least was being done for the child."**

**The parents were better able to cope with their children because the children were progressing physically or because they now had the feeling that something was being done to benefit their children or because their involvement with Conductive Education gave them new insights into the nature of their child's disability and ways to work with the child. This would result in a reduction of stress, felt the families.**

**Q.D.17. Parents' Openness To Discuss Their Children's Involvement in Conductive Education with the Professionals Involved with Their Child at Home.**

**This question sought to establish the level of openness between the parents and professionals at home, concerning their child's involvement with Conductive Education, in the light of the negative view taken by the professionals generally concerning it.**

**43 respondents answered this question. 2 of the respondents had already had their child's services withdrawn from them. 1 of these did not answer the question and the other answered it as not applicable.**

PROFESSIONAL AWARENESS		
Yes	No	Total
37	6	43

**Parents were asked whether the professionals at home were fully aware of their child's involvement with Conductive Education.**

**2 5% of the respondents informed some of the professionals involved with their child about of their child's involvement. One family chose to tell only those professionals who they felt might approve:**

**"some of them are not, most are."**

**1 explained why they felt some of the professionals might disapprove:**

**"Yes and No. Some did not approve of spending money outside the country."**

**1 family who had already had their services withdrawn had no professionals with whom to discuss the situation:**

**"There were no professionals dealing with him i.e. C.P.I., C.R.C. on a full time basis."**

**2 5% of the respondents were made immediately aware of the professionals opinion of their decision:**

**"totally against Conductive Education."**

**"The surgeon my daughter attended every six months in the C.R.C. was very annoyed and abrupt and impossible to deal with ever since."**

**and 1 respondent was determined to inform the professionals whatever the consequences:**

**"Yes, I saw no reason to hide the fact that I wished to do this regardless of the consequences."**

**Other respondents though, chose not to inform the professionals:**

**"No, advised by other parents not to discuss Conductive Education with professionals."**

**Some felt it advisable not to discuss the decision with professionals because of an awareness of the possible consequences:**

**"No, they did not agree with C.E. and would not give a service to my child if they knew."**

**Some of the first "soundings out" of the professionals were negative:**

**"Yes for first visit but No for subsequent visits - professionals did not have a good opinion of Conductive Education. We felt it was best if they did not know our business."**

**"No. I was told when she is old enough they will get her a wheelchair. And not to build up my hopes when I asked about Conductive Education."**

**In 6 14% of the 43 cases parents chose not to make any or all of the professionals dealing with their child aware of the fact that they were receiving Conductive Education. This would be indicative of both the parent's awareness of the professionals' antipathy to Conductive Education and of the gulf which existed between some families and some professionals.**

**Q.D.18. The Reaction of Professionals to the Fact that a Child was Undergoing Conductive Education.**

**This question sought to establish the reaction of the professionals at home to their clients receiving Conductive Education.**

**43 respondents answered this question. The respondent who did not answer was one who did not make professionals aware that they were involved with Conductive Education. All the other respondents who answered 'No' or 'N/A' to question D17 answered this question. This may mean that although these parents never discussed their involvement with Conductive Education with the professionals, they were aware that the professionals knew of that involvement. Or it may be that in their answer to this question these parents were predicting how they believed the professionals would react if they had been fully aware.**

**4 respondents gave answers outside the given categories. Their responses were therefore not charted but are reported below.**

PROFESSIONAL REACTION TO CONDUCTIVE EDUCATION						
Supportive	Accepting but not supportive	Uncooperative	Critical	Totally opposed	Other	Total
4	18	6	5	6	4	43

**Only 4 9% of the 39 responding families received uncritical support from the professionals with whom they were dealing. 4 respondents elaborated their answers to explain that different professionals reacted in different ways:**

**"Some were supportive but others were totally opposed".**

**3 of these 4 respondents drew a distinction between the reactions of those professionals who would be closer to the families on a day to day basis and those professionals in the Central Remedial Clinic:**

**"Locally supportive and C.R.C. uncooperative."**

**"My own doctors were very supportive but the C.R.C. in Dublin, totally opposed."**

**"Her school and Clinic accepting but not supportive,  
her neurologist in C.R.C. critical".**

**These responses may suggest that those professionals with a closer relationship with the families are likely to be more understanding of their decision to look outside the system for help. And the Central Remedial Clinic, as the foremost centre for the treatment of children with disabilities, may be more inclined to see this decision as a threat to its reputation. Whatever the reasons may be, the great majority of families may have felt alienated from the professionals dealing with their children by their decision to turn to Conductive Education.**

**Q.D.19. Withdrawal of Services to Children because of Receiving Conductive Education.**

**This question sought to establish the level of service withdrawal because of families involvement with Conductive Education.**

**All 44 remaining respondents answered this question.**

SERVICE WITHDRAWAL		
Yes	No	Total
14	30	44

**2 5% of the respondents who answered 'No' were not, in fact, receiving any therapy as their services had already been withdrawn.**

**1 other respondent who answered 'No' was threatened with service withdrawal and therefore kept subsequent visits to Budapest secret from the professionals.**

**14 31% of the 44 respondents experienced some level of service withdrawal as a result of their involvement with Conductive Education. Most of these children had all of their services withdrawn although 2 continued to be seen by some professionals:**

**"Yes. To date my child has been refused physiotherapy by the C.R.C. while I continue to attend the Peto Institute. She still receives Occupational Therapy once a month and sees a physiotherapist two or three times a year for assessment."**

**"The Neurologist and physio. in the C.R.C. did not wish to see her again. Her eye-specialist and psychologist in the C.R.C. continued to see her."**

**1 respondent whose children had their services withdrawn received help and support from another source:**

**"Physiotherapy programme at the C.R.C. was stopped but in their school their P.E. teacher put a lot more work into them and I would say helped very much to get them at the stage they are at now."**

**9 64% of the 14 respondents who had their child's services withdrawn identified the major centre for the treatment of children with disabilities as the institution which withdrew services from the children even to the extent of refusing to carry out required surgery:**

**"Physio. was withdrawn at the C.R.C. Also consultant there refused to carry out hip surgery due to attending Peto Institute."**

**1 respondent wrote of the excuse that was given for her daughter not receiving a service and expressed her feelings about the C.R.C.:**

**"My daughter did not receive an appointment for two years after that and when I enquired I was told the file was mislaid. I am very disillusioned with the C.R.C. and I find it hard to support their efforts."**

**1 respondent gave her opinion as to why the Clinic withdrew her child's services:**

**"sometimes they think that if they can't do anything to help no-one else can."**

**Withdrawal of services to the child was used repeatedly as a threat to try to coerce the parents into complying with the wishes of the professionals:**

**"His physio refused to work with him if I did not give a commitment not to have any more Conductive Education. C.R.C. withdrew services completely."**

**Some families solved this dilemma by not informing the professionals of their continued involvement:**

**"After we went to Budapest we were told that if we went again he would not be treated, so anytime after that we did not tell them when we went for C.E."**

**1 respondent feels that it was her involvement with Conductive Education which precipitated her son's transfer from the service provider which he had been attending. She also wrote of the contrast of attitude between Budapest and home:**

**"A short time after 1st trip I was forced to go to [service provider] who could offer me nothing but placed his name on their books. He was now one of**

**their clients on a waiting list for 3 years. I was now alone with him. The [Peto] Institute differed completely in approach to the child. They were warm and affectionate. You felt they cared."**

**Most parents were helpless in the face of service withdrawal but one respondent successfully fought such an attempt:**

**"They attempted to but I fought tooth and nail and won. Physiotherapist was attempting to withdraw services because I was requesting too much as a result of C.E., but I asked for a meeting with the paediatrician and as a result we were referred to the C.R.C. to Orthopaedic and everything was granted. We changed physios in [home town ] as a result."**

**Interestingly the parent managed to maintain her child's service by requesting a transfer to the C.R.C. - the centre which withdrew services from so many of the respondents' children. This would suggest some lack of consistency in their approach; in response to pressure from within the profession some chinks are appearing in the armour. This is the result of one resolute parent 'taking on' the system.**

14 32% of respondents experienced total or partial service withdrawal of State-resourced services from their children as a result of the parent's decision to take their child to Budapest. This would suggest that some professionals have no qualms about using the threat of withdrawal of their labour and skills in order to put pressure on parents to conform to their wishes.

**Q.D.20..Parents' Perception of the Standard of Professionalism of the Staff at the Peto Institute.**

This question sought to establish what were the professional attributes which the families found most satisfactory at the Institute.

38 respondents answered this question. 1 of the 6 respondents who did not answer the question also did not take any further part in the survey having apparently missed the last page of the questionnaire. There was no obvious reason why 2 of the other respondents failed to answer the question. The other 3 respondents were among the 5 who had not received Conductive Education in Budapest and did not adapt the question to comment on the Centres in which their children did experience Conductive Education.

Parents were asked how they would rate the Institute highly in terms of 'professionalism', 'skill', 'understanding,' 'attentiveness', and 'patience'. It was intended that in response to this question parents would indicate the one attribute which they found most impressive about the staff at the Institute. However only 11 of the 38 respondents confined themselves to one response. This may be because the question was ambiguously phrased and was therefore misunderstood or it may be that parents were simply unwilling to choose one attribute over the others. 1 respondent wrote:

**"I think it would score highly in all of these, it is difficult to pick just one."**

Of the 11 respondents who indicated just one attribute one indicated 'professionalism', one indicated 'skill', 4 indicated 'understanding' and 5 indicated 'patience'.

18 47% of respondents rated the Institute highly in all of the given categories and 1 respondent was very emphatic:

**"All very much so"**

**7 18% respondents listed their preferences with 'professionalism', 'skill' and 'patience' featuring highly in all of these.**

**1 respondent replied that the Institute scored highly in terms of 'skill' and 'understanding' but went on to write:**

**"very good for children but not fully understood how difficult it is to be a parent and have to push your own child all the time."**

**This would suggest that she felt that the understanding which existed for the children was not there to the same extent for the parents.**

**2 5% other respondents noted a deterioration in standards over time:**

**"Professionalism -1st time Yes. All other times No."**

**"In the beginning Yes, towards the end of our stay No. We were there between 1987 and 1990"**

**This deterioration in standards has also been noted in the answers to other questions.**

**1 respondent chose all the options but added:**

**"especially patience."**

**and this would reflect the position of patience as the most commonly chosen attribute. It was cited by 29 76% of the respondents.**

**Apart from the 2 5% of respondents who noted a deterioration in professional standards at the Institute over the years, the great majority of respondents were overwhelmingly positive about the standard of professionalism at the Institute. This value judgement must also serve as a contrast to the perceived standard of professionalism which the families experienced at home.**

**Q.D.21. Parents' Comparison of Results Achieved By Conductive Education with Those Achieved at Home.**

**This question sought to establish how the respondents rated the achievements of Conductive Education as compared to the results which are achieved at home.**

**40 respondents answered this question. One response did not actually answer the question and therefore the total is given as 39. It is not apparent why the remaining 3 respondents did not answer this question.**

PARENTAL COMPARISON OF RESULTS ACHIEVED					
Much worse	Worse	The same	Better	Much better	Total
0	1	1	14	23	39

**39 respondents answered this question and a large majority 37 95% of these felt that Conductive Education achieved better results than is achieved at home.**

**One respondents felt that it**

**"depends on the child."**

**and 2 5% respondents felt that the physical results were just 'slightly better' although 1 of these saw other benefits:**

**"Physically - slightly better, much better alertness due to extra stimulation."**

**The answer of the respondent who replied that the results are worse than are achieved at home is inconsistent with her responses to other questions and may be a result of a misunderstanding of the question.**

**Having gone through the process of making the decision to go to Budapest, arranging the finances, coping with the journey, with language problems, with living away from home and separation from family and friends, and having probably run the gauntlet of professional disapproval at home for their decision and possibly had their child's home services withdrawn, the fact that 95% of respondents rated the results achieved by Conductive Education as better or much better than those achieved at home, must be considered a forceful endorsement of those results.**

**Q.D.22. Improvement in Parents' Understanding of Their Child's Condition as a Result of Conductive Education.**

**This question sought to establish if involvement with Conductive Education increased the parents understanding of how to deal with their child's disability. If this proved to be the case it would represent a major benefit to the parents as earlier questions have established that they were left largely without information about, or support in dealing with their child's condition, by the professionals at home.**

**All remaining 43 respondents answered this question.**

<b>IMPROVEMENT IN PARENTAL UNDERSTANDING</b>				
<b>Not at all</b>	<b>More or less</b>	<b>Definitely</b>	<b>Very much so</b>	<b>Total</b>
<b>1</b>	<b>8</b>	<b>22</b>	<b>12</b>	<b>43</b>

**Only 1 respondent answered negatively and 34 79% of the 43 respondents were emphatic in their assertion that they had a better**

**understanding of how to handle their child as a result of involvement with Conductive Education. Thus parents would have experienced a great relief from the trauma which they earlier suffered as a result of isolation and lack of knowledge.**

**Q.D.23. Parents' Perception of Whether They and Their Child are in a Better Position as a Result of Involvement with Conductive Education.**

**This question sought to establish the degree to which parents might believe that the experience of Conductive Education was a beneficial one for themselves and their child.**

**40 respondents answered this question. The 3 respondents who did not answer were among those whose children had received Conductive Education only outside Budapest and did not chose to comment on Conductive Education as they experienced it.**

PERCEIVED IMPROVEMENT IN FAMILY'S CONDITION					
Not at all	Hardly	More or less	Definitely	Very much so	Total
1	2	4	16	17	40

**33 83%** of the 41 respondents were emphatic that they were in a better position as a result of their involvement with Conductive Education. Normally benefits have to be evident if people have to undergo difficulties in order to achieve them. If this is so, it could either be argued that given the difficulties involved in going to Budapest this is a high percentage, or that possibly parents need to perceive this to be so in order to justify the time, expense and effort which they endure.

**1 respondent answered :**

**"Difficult to say as we didn't continue with Conductive Education."**

**Only 3 8% respondents felt themselves 'hardly' or 'not at all ' in a better position as a result of their involvement with Conductive Education.**

**Q.D.24. Lessons Which Conductive Education could Teach Western Therapists.**

**This question sought to identify the perceived key differences between Conductive Education and the therapy which their children received at home.**

**41 respondents answered this question. 5 respondents failed to answer this and the final question.**

**The 41 respondents who answered this open-ended question gave 51 responses which can be loosely grouped giving an insight into the parents' understanding of the meaning of professionalism in Conductive Education by contrast with Irish therapeutic practice.**

**26 51% of responses focus on the parents' requirements for change in the system available in Ireland. Respondents noted a lack of any planned, systematic approach to the management of the child's disability. 7 14% of respondents cited the positive attitude of the Conductors towards the child:**

**"I think they are more positive about what can be achieved - the attitude is very different."**

**while others contrasted this with the perceived lack of professionalism of Irish therapists:**

**"To put more time and effort and patience into their day's work. The Conductors' hours in Peto are 8 full hours. No coffee breaks every five minutes."**

**The issue of patience was raised in 6 12% of cases, with Western therapists stated to be lacking in patience towards both child and parents:**

**"To be more positive and have a better understanding and patience with the Cerebral Palsied child and their parents."**

**1 respondent felt that Western therapists have lost sight of the basics:**

**"Get back to basics and give the children time and love - no need to spend so much on expensive equipment and drugs. In the West if one gets very sick one will get expert attention immediately but follow-up care very poor because professionals are not prepared to spend time with patient. Time is the most crucial factor."**

**Some parents felt that Western therapists put less effort into their work than do Conductors leading to poorer results as:**

**"You get from the child what effort you invest."**

**The power of Conductive Education to motivate a child in contrast to the Irish therapists' inability to do so was mentioned by 10 24%, respondents. Such motivation enables a child to work happily while being pushed to achieve his potential:**

**"Conductive Education pushes a child to the limit of its ability - here children are not pushed at all to try to do anything for themselves."**

**Motivation was also seen to involve recognising that a child with a disability is first and foremost a child:**

**"The personality first, handicap second, e.g. lazy child with Cerebral Palsy, whereas here - handicapped child who won't do anything because he is lazy."**

**"To see the child as a person, to have more patience with them (a wider outlook as regarding exercises) and to teach the children to be independent."**

**10 responses, 20%, focussed on the idea that Western therapist should adopt the more holistic approach of Conductive Education:**

**"To treat children as a whole person by one person - not to have one therapist working on her hands for 30 minutes, another with her legs for 30 minutes, another with her speech for 30 minutes etc. There are too many professionals involved with our children in the West."**

**A combining of the different Western professions, along with a change in attitude was considered an essential change to be made at home:**

**"That one therapist dealing with occupational therapy and physio. more effective. Conductive Education Conductors seem to communicate and enjoy children more and their methods of getting the child to do physio and rewarding achievements better. Conductive Education would indicate that intensive and regular therapy does benefit the child."**

**This idea that a change in the structures of the system in the West would bring about the perceived necessary change in the attitudes of the professionals was also hoped for by one of the two respondents who emphasised the importance of group work for the children:**

**"But if they had a group system like Peto perhaps they would learn skill, patience and be prepared for total dedication and understanding of each Cerebral palsied child's individual needs."**

**3 6% of responses indicated that the West should look to Conductive Education for a new system of training and approach to children with disabilities:**

**"The physios here know it all in theory - but it is a different thing putting it into practice. It's all about one's approach to Cerebral Palsy."**

**Indeed 1 respondent felt that Conductive Education could teach Western therapists :**

**"everything there is to know about handling children with handicaps. And I think now in 1994 Ireland should send people to Hungary to train for our own children."**

**Only 1 respondent felt that Conductive Education had nothing to teach Western therapists:**

**"If the same effort to raise money was spent here in Ireland it would benefit more children and parents overall. No miracles in Budapest. Too much hype."**

**The fact that an overwhelming majority of parents 98% felt that Western therapists had lessons to learn from Conductive Education shows a deep disappointment and disillusionment with almost every aspect of Western training, approach and attitudes. Parents question the efficacy of a system which seems to involve too many professionals without a holistic or even a planned approach to the child's**

**habilitation. The professionals themselves are perceived to be lacking in dedication, patience, understanding and ability to motivate the children or to appreciate the possibilities of their potential.**

**Western therapists would no doubt reject much, if not all of this criticism. It could be suggested, however, that it is less relevant to establish whether or not these criticisms are justified than it is to establish that these are the parents' perceptions of the therapist and the therapeutic system. The parents involved in this survey appear to be rejecting the 'laid back' non-involved approach in Ireland with its emphasis on theoretical professionalism as opposed to committed systematic, holistic approach requiring effort, persistence, skill and understanding.**

**Q.D.25. Parents' Perception of a Change in Therapeutic Practice Brought about by Conductive Education.**

**This question sought to establish whether parents perceived a change in therapeutic practice in Ireland as a result of families turning to Conductive Education.**

**41 respondents answered this question and their answers can be classified into four categories: 'Yes', 'Qualified Yes', 'No', and 'Qualified No'.**

**The majority of respondents 21 51% felt that therapeutic practice in Ireland has not changed at all and the frustration created by this is evident in some of the answers:**

**No. They do not have the dedication. All they want is a wage packet - they know Conductive Education means hard work for them and they are not prepared to give. They are so negative it's not true - ask anyone attending the [clinic]. When a child reaches the age of 14 - 15, every three weeks they are told about their handicap and all the things they will never be able to do. Also how different they are from other children. Would you call that positive? I have refused my daughter to be brought into this class as I don't want her listening to these negative things. I never allow her to say 'I can't'. As far as she is concerned she can walk, talk, see and speak. I was told by the [clinic] I was not being realistic but she can do these things, maybe**

not walking as good as us but nevertheless she walks. And to her she's as good as we are. She has been told from an early age about Cerebral Palsy and she accepts some of the things she is not allowed to do at present, (boiling a kettle, making coffee), but we are working on it. She washes delph, makes her own bed, hoovers, etc. and loves to be included - these are the positive things. Who wants to hear the other, it's bad for the morale of the child."

"Some say we already have Conductive Education in Ireland (I doubt it). There is a curiosity mixed with a sneering negativity. Perhaps if jobs were not in question, they would open the debate readily. There is some movement but not enough to raise a question in the Dail. My son has completed three years Montessori school due to the fact that we went to Budapest. Nappy training and walking ability were part of the necessary requirements for his school. I stayed in the school and went through the Montessori equipment using the techniques of Conductive Education. He proved a lot of people wrong. The worst thing in following Conductive Education in Ireland is the lack of follow - up and back - up. My son is now six and a half years old and in a full time place with [mental handicap service provider]. It offers me respite but I know if he had a Conductor he would be better off. I cannot be my son's teacher for every waking moment and have to depend on people working in the services who need better knowledge. After three years of my slogging, they sent him home in a nappy one day. They just don't understand. The frustrations live on."

**4 10% respondents answered the question with a qualified 'No':**

"No, maybe a little."

"I would imagine the main reason people travelled to Peto was because of the publicity about Peto. The very same work could be done very easily and maybe get the

**child orientated to physio at a very early age and doing things the right way but all of this is a very tedious job - I don't think many people would be interested in it. Not unless it was very well paid."**

**2 5% respondents answered that they did not know if practices had changed and a further 2 5% stated that they could not know because their child was excluded from services:**

**"I don't really know because my daughter doesn't have any therapy, - only what I give her."**

**6 14% of respondents answered the question with a qualified "Yes":**

**"Yes, slowly."**

**"Marginally, because Conductive Education has raised parents' level of expectation and do not as easily accept platitudes from professionals."**

**6 14% of respondents felt that the fact that so many families travelled to Budapest has changed therapeutic practice in Ireland:**

**"Definitely opinion is that Irish therapists came out of their boxes - I think they took over many good points e.g. furniture, massage (safe). I think that they learned a great deal from parents about treatments - if they listened and helped to carry on some exercises.**

**"It has probably broken down the barriers and made the therapist provide a better service and a greater variety of methods."**

**12 29% of respondents felt that therapeutic practice had changed as a result of families travelling to Budapest for Conductive Education. Parents travelled to Budapest as individuals, as personal statements of their own dissatisfaction with the level and quality of therapeutic provision which they were receiving at home. That the combination of these individual actions should affect the provision available at home must provide satisfaction to those parents. However, for the majority of parents their individual satisfaction with Conductive Education was not compounded by a perceived change in the therapeutic provision at home.**

## **SUMMARY OF SECTION D.**

**It was established in the previous sections that the majority of parents involved in this survey were dissatisfied and frustrated by the therapeutic provision available to their disabled children at home. Section D looked at the experiences of the families through their involvement with Conductive Education. It looked at their first contact with Conductive Education, at their reactions to the journey to Budapest, living in Hungary and to the funding of their visits. The Section asked for the parents' assessment of the provision available at the Peto Institute and asked for their perceived comparison of the provision available at home with that available in Budapest. Other questions explored the reactions of the professionals at home to the families' involvement with Conductive Education and finally this section asked for the parents' perception as to whether provision at home had changed as a result of families travelling to Budapest.**

**It was established that most parents [76%] received their first information about Conductive Education from the media with just 6% receiving such information from professionals.**

**The most commonly cited [30%] reason why parents felt that Conductive Education would benefit their children was that they were dissatisfied with the provision available to their children at home. This sense that the decision to turn to Conductive Education was based, in many cases, on a disillusionment with the available provision is reinforced by the 7% of respondents who cited**

**'desperation' as their reason for turning to Conductive Education. Some parents, however, were turning TO Conductive Education as much as they were turning AWAY from home provision with 23% of respondents stating that they believed that they would achieve good results from Conductive Education and 27% feeling that it was 'worth a try'. Other parents were attracted by the method itself [21%] and 6% of respondents were seeking a better understanding of their child's condition.**

**Most parents stated that prior to turning to Conductive Education they perceived the Conductive Education approach as qualitatively different as regards professionalism, understanding and method. Yet as their information at that stage was based mainly on media reports, it could be suggested that the parents were actually making a statement concerning the defects which they perceived in the provision available to the families at home.**

**In seeking to establish the parents' most compelling motive for turning to Conductive Education the answers had both a positive and a negative aspect. Parents turned to Conductive Education both because it offered 'great hope for the child' [30%], but also because of 'dissatisfaction with the present system'. The anxiety that the available provision was causing to parents can once again be seen in the 30% of respondents who cited 'desperation' and 'guilt' as motivating factors for undertaking Conductive Education.**

All but one of the respondents received family support for their decision to turn to Conductive Education and 93% of respondents received 'good' or 'fullest' family support. A high level of support was also provided by the families' communities, with 83% of respondents to this question stating that they received such support. One practical way in which this support was given was in the area of fundraising, without which many of the families would not have been able to travel to Budapest. 73% of the respondents relied on fundraising to some extent to finance their involvement with Conductive Education and visits to Budapest.

Two of the families lived in Budapest for periods of two and three years. 63% of the respondents had at the time of answering the survey, returned to Budapest at least three times. Given the difficulties associated with travelling to Budapest this shows a high level of commitment to Conductive Education. One family employed a Conductor at home for two years and other families experienced Conductive Education in Ireland, either in addition to or instead of travelling to Budapest. Five families employed a Conductor at home during school holidays and eight families experienced Conductive Education in Summer Camps or in centres in Northern Ireland. Thus, not only have parents shown a commitment to Conductive Education by travelling repeatedly to Budapest, but they have also imported the method privately into the country to an extent that is unprecedented.

Parents also displayed their commitment to Conductive Education by the fact that they were willing to travel to Budapest for visits of short duration. The majority of all the visits to Budapest were for periods of one month or less. It is indicative of the perceived benefits that parents felt were accruing to their children, that many families returned three or four times to Budapest for visits of two or three weeks duration. This commitment was particularly striking in the case of the 49% of respondents who found travelling to Budapest to be 'extremely arduous' or 'difficult' and even in the cases of the further 22% who found the experience just 'bearable'. Almost one third of the respondents, however, found the travelling to Budapest to be 'very enjoyable' or 'pleasant' with two respondents noting that it became easier.

The responses showed an overwhelmingly [but not unanimously] positive perception of the abilities of the staff at the Peto Institute. 49% of respondents perceived the staff as 'highly professional', 29% as 'very skillful' and 15% as 'knowledgable'. Three respondents were more critical of the staff at the Peto Institute. One parent felt that not all the staff reached the same standards and two other parents noted a decline in professional standards over the period during which they attended the Institute.

A decline in standard and other internal problems within the Institute were cited by 19% of respondents as the biggest disadvantage of the Peto Institute. The Institute lost a lot of Conductors during the early years to Western countries where they worked either in centres or in

**individual homes. This fact, coupled with the overwhelming demand for places at the Institute led to what many parents perceived to be overcrowding in the groups and to poor Conductor / children ratios. The most commonly expressed disadvantage, [41%], however, arose from difficulties caused by distance, isolation and the splitting up of families. 25% of respondents cited the language barrier as the greatest disadvantage and 12% cited the journey. 5% of respondents were concerned about injuries which their children suffered while attending the Peto Institute and 5% felt that the length of time they were able to spend at the Peto Institute was too short. 10% of respondents could see no disadvantage to the Peto Institute at all.**

**Notwithstanding the disadvantages perceived by the parents, all the respondents felt that the benefit which their child derived from the Peto Institute lived up to their expectations. In the majority, [62%], of cases the parents expectations were 'very well met'.**

**68% of responses marked physical improvements in the children's condition which included improved sitting, standing, walking and speech abilities and some parents compared this progress with what might have been achieved at home. 10% of respondents noted that their child's work-rate and improvement continued after the children returned home. The holistic approach of the Peto Institute was valued by parents as was the Conductors' ability to motivate the children and inspire them with a positive attitude.**

**Two of the thirty-nine respondents who answered this question felt that their children did not derive any benefit from treatment at the Institute, although one of these felt that this was because they were not there for long enough.**

**Five [12%] of respondents noted little or no improvement in their children's condition as a result of their involvement with Conductive Education. 19% of respondents felt that their child's physical condition had 'more or less' improved and the majority - 70% - reported a 'definite' or 'very definite' improvement.**

**Involvement with Conductive Education results in the majority of parents feeling themselves to be better able to cope with their child's disability, which would have the effect of reducing any trauma which those parents were experiencing. 77% of respondents felt that their involvement with Conductive Education 'definitely' or 'very much' improved their ability to cope. 18% of respondents felt that their ability to cope was 'more or less' improved and 5% of parents did not experience an improvement in their ability to cope with their child's condition as a result of their involvement with Conductive Education.**

**Most families [84%] made the professionals at home who were dealing with their children aware of the child's involvement with Conductive Education. Some, however, chose to tell only those who they thought might approve and 14% chose not to make all or any of the professionals aware, which would indicate a lack of trust and openness within those parent - professional relationships.**

**Only 9% of respondents received uncritical support from the professionals, 56% experienced lack of cooperation or support and others were faced with criticism and total opposition. Three respondents drew a distinction between the reactions of those professionals who were closer to the families on a day to day basis and who tended to be supportive, and those professionals based in the Central Remedial Clinic who tended to be more critical.**

**The disapproval of the professionals led to 32% of respondents experiencing some level of service withdrawal, whereby professionals refused important therapeutic provision to the children because they were displeased with the parents' decision to involve the children in Conductive Education. Once again, the Central Remedial Clinic was named repeatedly as an agency which withdrew services from the children or used the threat of such withdrawal to try to discourage the involvement with Conductive Education. However, against the trend, one family had their child's services restored as a result of transferring the child INTO the care of the Central Remedial Clinic.**

**Prior to visiting the Peto Institute, parents had expectations of high professional standards. These expectations appear to have been justified as 95% of parents were very positive about the standard of professionalism which they experienced at the Peto Institute. 5% of respondents, however, noted a deterioration in professional standards over time which was also noted in the responses to some other questions.**

**95% of respondents felt that Conductive Education in the Peto Institute achieved better results than are achieved at home. This must be considered an extremely forceful endorsement of Conductive Education given the difficulties which the parents encountered as a result of their decision to attend the Peto Institute.**

**The experiences of the families with the provision which was available to them prior to their involvement with Conductive Education was shown in earlier sections of this survey to cause them to suffer stress and anxiety. Their involvement with Conductive Education, despite the difficulties which it created, served to reduce the trauma of a majority of the respondents. 83% of respondents felt that they and their children were in a better position as a result of their involvement with Conductive Education.**

**The responses to the question as to the lessons which Conductive Education could teach Western therapists gives an insight into the parents' perceptions of the deficiencies in the Irish services. The lack of a planned, systematic approach to the management of childhood disability was noted by the parents and 14% of respondents felt that the Irish system lacked the positivism inherent in Conductive Education. Likewise, 24% of the respondents contrasted the power of the Conductors to motivate children with the perceived inability of Irish therapists to do so, and 12% of responses noted a comparative deficiency in the patience of the Irish therapists. The parents who answered this question are seeking a committed, systematic, holistic approach to their children's disabilities. Such an approach, they**

**suggest, would require a level of effort, patience, skill and understanding that does not currently exist in the Irish system.**

**29% of respondents felt that the Irish system is changing as a result of families turning to Conductive Education. Some of these parents felt that some therapists have taken on some of the principles of Conductive Education and others perceive a slow change in the system itself. One parent felt that this is because parents' levels of expectations have been raised and that they now demand a better standard of provision. However, the majority of respondents, [51%], felt that therapeutic practice has not changed at all as a result of families turning to Conductive Education.**

## **OVERALL CONCLUSIONS.**

**A certain portrait of the families who turned to Conductive Education emerged from the survey. The families were, in the majority, middle class and well educated. The families were almost all small or medium sized ones and the child with disability was generally within the 7 - 12 year age range. Thus the picture was that of a settled rather than a non-conformist group who were, however, well placed to seek an alternative to an unsatisfactory situation.**

**The time of diagnosis and early therapeutic provision was confirmed by the survey to be a defining period in the eventual decision of most of the parents who turned to Conductive Education. Many parents received a delayed or inaccurate diagnosis and very few received the required support or information. This left the parents isolated and distressed at a time of great emotional turmoil.**

**Whilst all the children eventually received physiotherapy, the majority waited more than one month for their first appointment. And the therapy was then perceived by parents to be too infrequent to be satisfactory. The parents' frustration was thereby increased rather than decreased by the therapeutic provision.**

**The quality of the therapy which the children received also proved to be a source of frustration and distress for the majority of the parents, with few perceiving it as satisfactory or effective.**

Despite their frustrations, few of the families turned to an 'alternative' therapy before making the decision to try Conductive Education. The parents were, therefore, not inveterate rebels or miracle chasers. Rather they can be seen as a largely conformist group until they found their own and their children's position to be untenable and an acceptable alternative became known to them.

The parents' decision to turn to Conductive Education represented both a turning away from the home-based provision, and the frustrations which it caused, and a turning to Conductive Education. And while few parents originally had any in-depth knowledge of the methods of Conductive Education, it was perceived by them to be superior in terms of professionalism, understanding and method.

Parents were well supported in their decision by their families and communities. This support manifested itself in terms of fundraising for most of the families which, in many cases, made their visits to Budapest possible.

The great majority of the parents perceived the staff at the Peto Institute to be of a very high standard. While there were some criticisms of both staff and organisation within the Institute, most of the expressed disadvantages were caused by distance, isolation, language and the splitting up of families.

Despite the disadvantages, the parents expectations were well met with a majority of parents noting physical improvements in their child's condition. Alongside this improvement, parents also expressed themselves to be better able to cope with their child's condition. Given the build-up of frustration which parents experienced prior to turning to Conductive Education, this would represent a great alleviation of their trauma. Almost unanimously, the parents felt that both they and their children were in a better position having experienced Conductive Education.

However, the parents' enthusiasm for Conductive Education was not, in most cases, shared by the professionals with whom they were dealing at home. Many professionals reacted critically to the families involvement and were uncooperative and disapproving even to the extent of withdrawing services from the children.

Despite the expressed disapproval of some of the professionals, some of the parents felt that the Irish system was changing slowly as a result of the enthusiasm of the parents for Conductive Education. The majority of parents, however, did not perceive this change.

The changes which the parents perceived to be required were stated in terms of raised levels of skill, understanding and commitment. The Irish system, as it was experienced by the parents, produced such a level of frustration and trauma in the parents that they were driven to seek an alternative. For this situation to be improved parents require

**the same planned, systematic, intensive system of care for their children based on skill, knowledge and positivism that they perceived they experienced with Conductive Education.**

**Parents require a timely diagnosis which is given sensitively and without an additional, incorrect, diagnosis such as one of a mental handicap.**

**Parents need to feel supported by the professionals in their times of crisis such as the period surrounding diagnosis. Information is crucial to relieve the trauma which parents may suffer and if professionals are unable or unwilling to offer support and/or information, they should inform the families of support groups to whom the families could turn.**

**Therapy should be a positive and beneficial experience for both the parents and the child with the disability. The desire of parents that Irish therapists be more patient, holistic, positive and understanding would seem to require little more than a change of attitude on the part of the therapists. Parents feel isolated and frustrated by their perception that the service providers are not working to the best interests of the families or the children. However, when parents feel that their children are receiving a beneficial service they also perceive their own situation as parents to be improved. This obviously leads to a reduction of the frustration and trauma which may be experienced by the parents.**

**The requirement of the parents that their children's therapy service be more intensive may necessitate an increase in resources. However, parents themselves are a resource that is under used. Parents are eager to benefit their children and they should be given the knowledge and the skills to confidently work with the children at home. Not only would this increase the amount of therapy which the children receive but would also involve parents more closely in the therapeutic process, relieving some of the isolation and frustration and bring about a greater partnership between parents and professionals. This can only be of benefit to all involved in the care of a child with a disability and, most importantly, to the child him or herself.**

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**APPENDIX A.**

**QUESTIONNAIRE FOR PARENTS OF CHILDREN WHO  
RECEIVED CONDUCTIVE EDUCATION.**

**This questionnaire is designed to collect information about the experiences of parents whose children received Conductive Education in the Peto Institute in Budapest and/or in the Peto Institute in Dungannon. Your impressions up to, during and after your visits to the Institutes are important in establishing the validity of this undertaking. Your answers to this questionnaire will be a very valuable contribution to this end.**

**This survey is being conducted on behalf of the National College of Industrial Relations, Sandford Road, Dublin.**

**ALL RESPONSES ARE CONFIDENTIAL.**

**SECTION A: BACKGROUND.**

**Please give some background information about your family and your child with Cerebral Palsy. Please circle the answer where appropriate.**

**A1. Are you the child's mother or father?**

**Mother      Father**

**A2. Are you:      single married seperated widowed other**

**A3. What age are you?      ----- years.**

**A4. Parents` occupation[s]. If parenting alone please answer only for yourself.**

**Mother`s occupation-----**

**part-time full-time**

**Father`s occupation-----**

**part-time full-time**

**A5. Parent`s level of education. If parenting alone please answer only for yourself.**

**Mother: National schooling Secondary schooling Third Level**

**Please specify any qualifications-----**

**Father : National schooling Secondary schooling Third Level**

**Please specify any qualifications-----**

**A.6. Total number of children in family-----**

**A7. Ages of children-----**

**Please circle the age of the child/children with Cerebral Palsy.**

**Please state whether this child is male or female-----**

**Date[s] of birth of child/children with Cerebral Palsy-----**

**SECTION B: DIAGNOSIS**

**Please give details of the circumstances in which your child was diagnosed as having Cerebral Palsy.**

**B1. At what age was your child diagnosed as having Cerebral Palsy?**

**Please specify years and/or months.**

**-----years -----months**

**B2. Who first suspected that the child might have a problem?**

**Mother Father Relatives Developmental Clinic G.P. District  
Nurse Other**

**If other, please specify-----**

**B3. Did you encounter any difficulty in obtaining a diagnosis?**

**Yes No**

**B4. What would you put any such difficulty down to?**

**ignorance incompetence professional pride concern for parents  
lack of certainty other**

**If other, please explain-----**

**B5. Was there a wrong diagnosis, e.g. a mental handicap which did  
not exist?**

**Yes No**

**If yes, please specify-----**

**B6. Did you seek a second opinion, or were you referred to another agency or specialist, e.g. the Central Remedial Clinic?**

**Yes No**

**If so, please give details-----**

**B7. How would you best describe your reaction to the news that your child had Cerebral Palsy?**

**relief normal surprise distress shock disbelief trauma  
other**

**If other, please specify-----**

-----

**B8. Did you know anything about Cerebral Palsy before your child was diagnosed?**

**Yes No**

**B9. After diagnosis, were you offered information about Cerebral Palsy?**

**Yes No**

**B10 How did you obtain information about Cerebral Palsy?**

**personal reading friends other parents professionals**

**B11 After diagnosis, were you informed about any support groups?**

**Yes No**

**If no, would you have welcomed such information?**

**Yes No**

**B12 Do you feel that you needed professional support at the time of diagnosis?**

**Yes No**

**B13 Did you receive such support at that time?**

**Yes No**

**B14 Was your child referred for physiotherapy after diagnosis?**

**Yes No**

**B15 How soon after diagnosis did this physiotherapy began?**

-----days -----weeks -----months

**B16 How regular was the physiotherapy?**

once weekly twice weekly once a fortnight once a month other

If other, please specify-----

**B17 Did you find the level of therapy adequate?**

Yes No

If no, please give your reasons-----

-----

**SUBSEQUENT TREATMENT.**

**Please give details of the treatment your child received up to and including years at school**

**C1. Did you ever seek services from outside your own area?**

**Yes No**

**If yes, was it:**

**different therapist voluntary body different Health Board  
other agency-----  
-----**

**C2. Did you ever try an alternate therapy e.g. Doman-Delacatto?**

**Yes No**

**Please specify-----  
-----**

**C3. If your answer to C1 or C2 was Yes, what was the reaction of the professionals with whom you were dealing?**

**approving accepting disapproving but tolerant unaccepting  
withdrawal of local services**

**C4. What other support did you get at this time?**

**family extended family friends community organisations**

**C5. Would you consider that the level of therapy that your child was receiving at this stage was:**

**very good good satisfactory poor very poor**

**C6. How effective was it in helping with your child's handicap?**

**very effective effective fair ineffective totally ineffective**

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**C7. What were your feelings about the services which your child was receiving?**

**very happy happy enough tolerant frustrated very angry**

**SECTION D.: CONDUCTIVE EDUCATION.**

**Please give details of your involvement with Conductive Education**

**D1. How did you first hear of the Peto Institute?**

**`Standing up for Joe` film newspaper/magazine friends  
professional advice other**

**If other, please specify-----**

-----

**D2. Why did you feel Conductive Education would be effective in  
helping your child?-----**

-----

-----

**D3. How did it compare to the service which you were already  
receiving?-----**

**highly professional approach much better understanding better  
method the same but more intensive**

**D4. What would you say was the most compelling motive for turning to Conductive Education?**

**great hope for the child   slight hope of improvement  
dissatisfaction with present situation   guilt   desperation   other**

**If other, please specify-----**  
-----  
-----

**D5. What kind of family support did you receive for your decision?**

**none   bad   fair   good   fullest**

**D6. How did you finance your visits-----**  
-----

**D7. Did you receive help from your local community?**

**Yes   No**

**D8. How many times did you visit Budapest?**

once twice three four five times other

If other, please specify-----

-----

**D9. How long did you spend there at each visit?-----**

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**D10 How did you find the travelling and your stay in Budapest?**

extremely arduous difficult bearable pleasant very enjoyable

**D11 How did you find the staff at the Institute?**

highly professional very skillful knowledgable attentive but  
not very good good but not very attentive

**D12 What did you see as the biggest disadvantage of the Institute?---**

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**D13 To what extent did the Institute live up to your expectations?**

**very badly   badly   fairly well   well enough   very well**

**D14 In what particular way did you feel that your child benefited most from the treatment at the Institute?\_\_\_\_\_**

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**D15 Did you feel your child's physical condition improved as a result of Conductive Education?**

**not at all   hardly   more or less   definitely   very much so**

**D16 Do you think that it helped you to cope better with your child's Cerebral Palsy?**

**not at all   hardly   more or less   definitely   very much so**

**D17 Were the professionals dealing with your child fully aware that your child was receiving Conductive Education?**

**Yes No**

**If no, please specify**-----

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-----

**D18 How did the professionals dealing with your child react to your child receiving Conductive Education?**

**supportive accepting but not supportive uncooperative critical totally opposed.**

**D19 Have you ever had services withdrawn from your child because of your involvement with Conductive Education?**

**Yes No**

**If yes, please specify**-----

-----

-----

**D20 In your opinion would the Institute score highly in terms of:**

**professionalism skill understanding attentiveness patience**

**D21 Compared to the results achieved at home, are the results achieved by Conductive Education?:**

**worse much worse the same better much better**

**D22 Do you have a better understanding of how to handle your child as a result of Conductive Education?:**

**not at all hardly more or less definitely very much so**

**D23 Do you think that you and your child are in a better position now than if you had not gone to Budapest?:**

**not at all hardly more or less definitely very much so**

**D24 What, if anything, could Conductive Education teach Western therapists?:**\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**D25 Has the fact that so many families travelled to Budapest changed therapeutic practice in Ireland?:**-----

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